

Learn the Signs. Act Early.

AMCHP's State Systems Grant: Eight Years (2011-2019) in Review

INTRODUCTION

The number of children identified as having autism spectrum disorder (ASD) and other developmental disabilities (DD) has increased significantly in recent years. According to the Centers for Disease Control and Prevention (CDC), approximately 1 in 59 children in the United States has been identified with ASD and 1 in 6 children has a DD¹. The rising incidence of ASD/DD and heightened focus on early identification and intervention has led to an increased demand on states to develop and improve systems of care to ensure that all children receive early developmental screenings and that those with ASD/DD receive timely identification, diagnosis, and intervention services.

Early childhood (ages 0–3) is a critical period that can set the stage for an individual's health trajectory. Thus, it is important to monitor and screen a child's development early on to ensure that potential delays are identified early. This also allows family members to celebrate child developmental milestones, such as walking, talking, and learning.²

Early identification of ASD/DD is achieved through developmental monitoring and developmental screening. However, it is important to note the differences between developmental monitoring and developmental screening. *Developmental monitoring* is an ongoing process in which

caregivers and health care providers observe how a child grows and changes over time. *Developmental screening* uses a validated screening tool to evaluate whether a child has met age-appropriate goals within the areas of communication, physical, cognitive, and social/emotional development.³ Early identification of ASD/DD allows children to receive earlier treatment and interventions, those of which are more effective in addressing delays and disabilities, and less costly than special education services in later childhood.⁴ These investments in early childhood programs and services can significantly improve a child's development.

The CDC's *Learn the Signs. Act Early.* (LTSAE) program was launched in 2004 to improve early identification of children with ASD/DD and to enable children and families to access the services and support they need. As part of this program, the Act Early state systems grants focused on the need to improve state capacity and strengthen state and community systems for early identification and coordination of services for children with developmental disabilities. This issue brief highlights the successes, challenges, and lessons learned from the state systems grants, as well as key strategies that contributed to sustainable improvements and changes in programs that serve young children and their families.

¹ Data & Statistics on Autism Spectrum Disorder. (2019, April 5). Retrieved March 31, 2019, from <https://www.cdc.gov/ncbddd/autism/data.html>

² Child Development. (2019, February 6). Retrieved March 31, 2019, from <https://www.cdc.gov/ncbddd/childdevelopment/facts.html>

³ Development Monitoring and Screening. (2019, February 6). Retrieved March 31, 2019, from <https://www.cdc.gov/ncbddd/childdevelopment/screening.html>

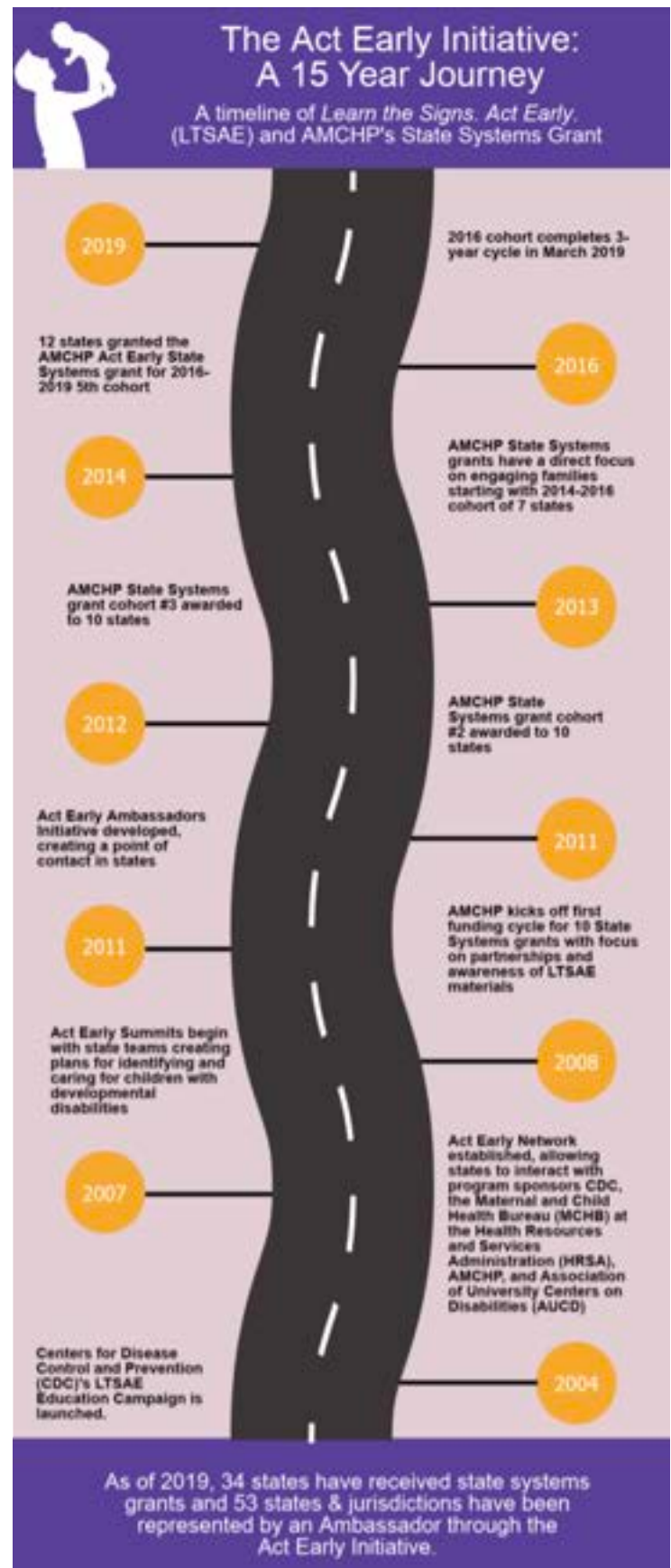
⁴ Autism Spectrum Disorder (2018, May 3). Retrieved March 31, 2019, from <https://www.cdc.gov/ncbddd/autism/facts.html>

BACKGROUND

L TSAE: Act Early Initiative.

The LTSAE program aims to improve early identification of children with ASD/DD so that children and families can get the services and support they need. The program has three components: Health Education Campaign, Act Early Initiative, and Research and Evaluation.⁵ The Act Early Initiative was designed to enhance collaborative efforts to improve screening and referral to early intervention services through relationship building with state, territorial, and national partners to improve early childhood systems.

As part of the Act Early Initiative, the Act Early Network was created in 2007 and convened Act Early Regional Summits throughout the U.S. from 2008–2010; during this period, states coordinated plans regarding capacity building to identify ongoing needs of children with ASD/DD. In 2010, the Association of Maternal & Child Health Programs (AMCHP) began the LTSAE state systems grants in order to complement state activities initiated during the Act Early Summits. To advance these efforts, in 2011, the Act Early Ambassador program established points of contact within participating states to disseminate LTSAE materials within systems and organizations that serve children and their families.



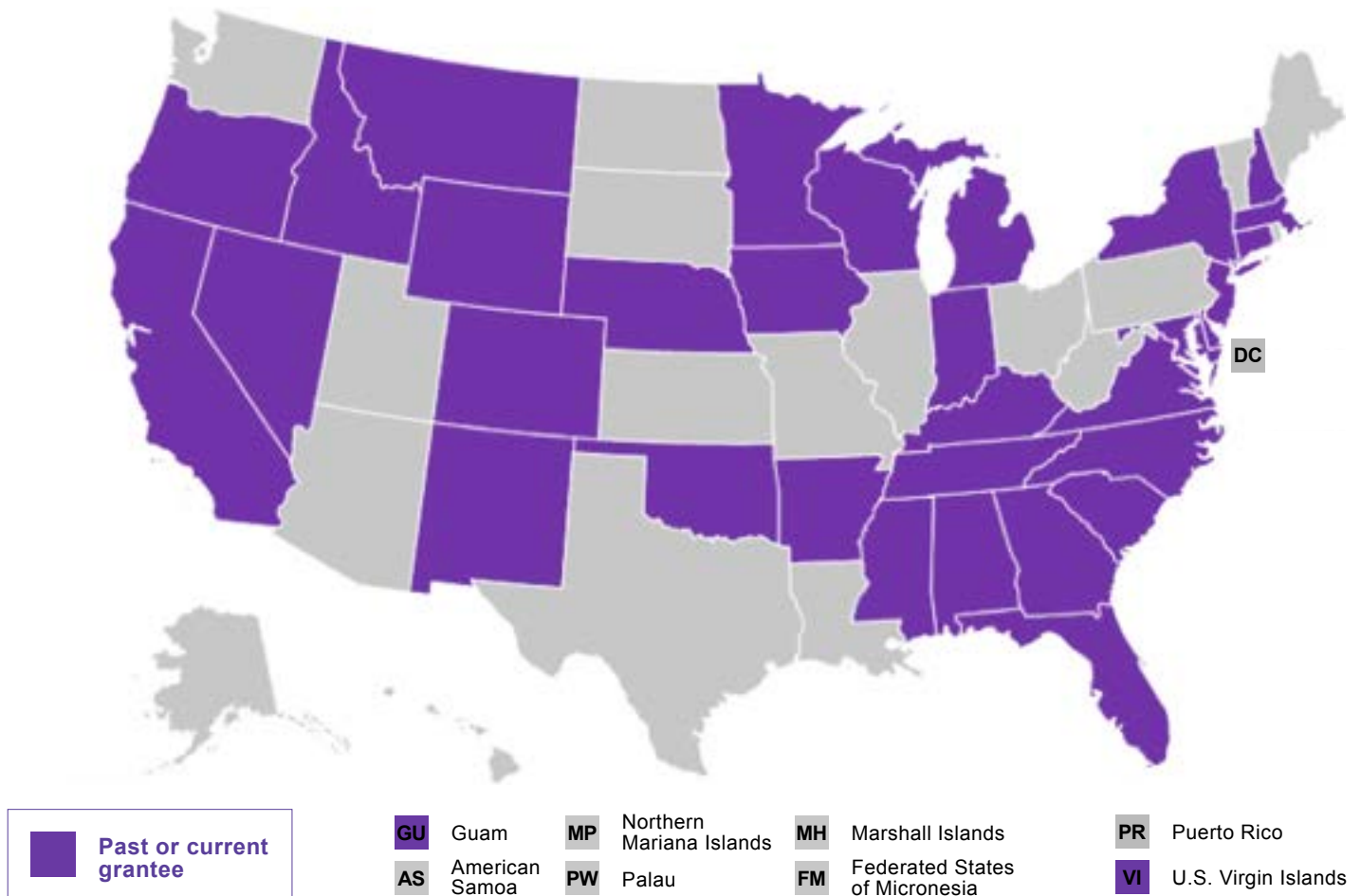
⁵ Learn the Signs. Act Early. (2018, May 29). Retrieved March 31, 2019, from <https://www.cdc.gov/ncbddd/actearly/about.html>

State Systems Grants.

The goal of the state systems grant is to strengthen state and community systems for early identification and coordination of services for children with developmental disabilities. Early grants focused on implementing action plans developed during the Act Early Regional Summits. Recent grants (beginning in 2014) have prioritized increasing family-engaged developmental monitoring. In addition to funding grants, AMCHP has provided quarterly technical assistance calls, connected grantees to other states and experts, and supported an interactive grantee listserv.

Through support from the CDC and in partnership with the Association of University Centers on Disabilities (AUCD), LTSAE state system grants have been dispersed among 34 U.S. states and jurisdictions (hereafter referred to as 'states') with 14 states participating in more than one cohort. With funding amounts between \$10,000 and \$20,000, the grantees have made strides in increasing developmental monitoring, developmental screening and early identification, and collaborations across early childhood programs. This issue brief highlights outcomes from the eight years of the state systems grant program.

AMCHP State Systems Grant Distribution



METHODOLOGY

AMCHP conducted an environmental scan of each grantee's applications, mid-year reports, final reports, and quarterly call summaries. Following the environmental scan, AMCHP administered a survey to grant leads in April 2018 to assess each grant's impact and outcomes, sustainability efforts and concerns, and comments not otherwise captured in the environmental scan. Grant leads from 31 states and jurisdictions responded, representing 91 percent of the grantees over the life cycle of the program. The environmental scan findings and survey results were analyzed for common themes.

FINDINGS

The survey findings were as follows:

- 29 grantees (94 percent) agreed that they had achieved their goals for the LTSAE State Systems Grant; of these grantees, 19 (61 percent) reported that they strongly agreed.
- More than 90 percent of grantees reported that awareness of the importance of developmental monitoring and screening had improved, and so did the providers' knowledge and training within the state systems.
- 82 percent of grantees reported that having the grant in place helped create, strengthen, or sustain partnerships with family or parent-based organizations, Maternal and Child Health (MCH), and Children and Youth with Special Health Care Needs (CYSHCN) programs.
- 94 percent of grantees believed their grant-related efforts remained sustainable or somewhat sustainable after the funding ended.

The majority of grantees partnered with parent organizations, state MCH/CYSHCN programs, universities, community organizations, Part C/Part B Child Find programs, Head Start/Early Head Start, child care programs, and provider groups (e.g. American Academy of Pediatrics (AAP) chapters) and clinics. Additional partners included home visiting programs, school alliances, libraries, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) programs, and other agencies and organization such as centralized points of entry (e.g., 2-1-1 United Way), state departments of education, and policymakers.

The survey also asked grantees to identify areas of improvement they noticed as a result of conducting their state systems grant work. Qualitative analysis of this data revealed three main areas of impact – or impact points – reported by grantees:

- Formalized developmental monitoring and early identification as a priority
- Activated stakeholders and strengthened partnerships
- Increased awareness among caregivers and providers

A summary of each impact point, along with grantee implementation examples, is described below.

Partner Organizations



Figure 1 shows the myriad of partners that the LTSAE state systems grantees worked with to achieve their goals. Each specific organization or entity (e.g., hospitals) is represented by a bubble; the size of each bubble represents the number of grantees that it partnered with. For example, a larger number of grantees partnered with parent organizations than with libraries. State grant project leads were situated in various organizations, such as University Centers for Excellence in Developmental Disabilities (UCEDDs), Title V MCH and CYSHCN programs, other public health human services departments, health systems, and nonprofit organizations.

Impact Point: Formalizing Developmental Monitoring and Early Identification as a Priority

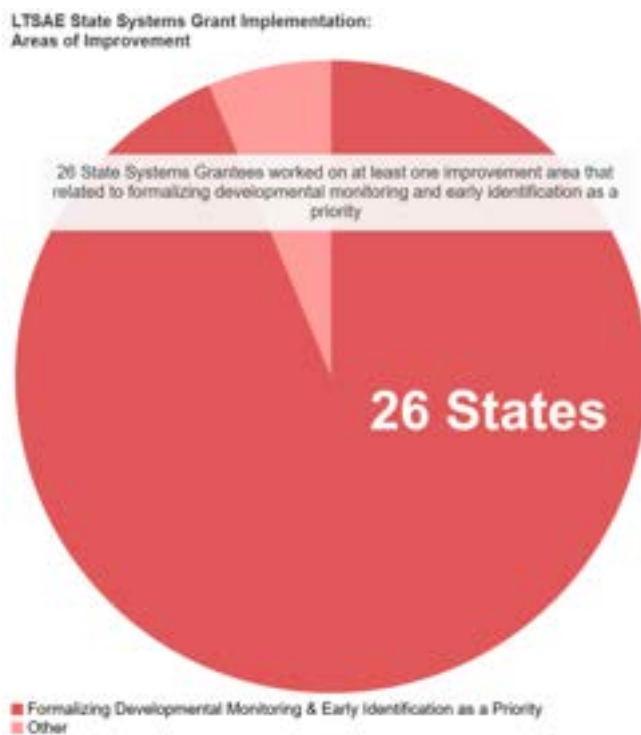
Figure 2 highlights the first of the three major impact points of the LTSAE state systems grant. 26 states worked on at least one improvement area related to formalizing developmental monitoring and early identification as a priority. The majority of states that worked on these areas agreed that the grant led to the following types of improvements:

- Integration of system uses of LTSAE information/materials in some regular activities (n: 26 out of 26)
- A policy or practice has been changed or created to conduct developmental monitoring and screening (n: 22 out of 25)
- A policy or practice has been changed or created for better coordination of early identification and early intervention services (n: 19 out of 23)

By bringing systems, agencies, and groups together around common goals and activities, grantees noted that they were able to impact state systems by formalizing and solidifying a commitment around developmental monitoring and early identification. The earlier rounds of the grants focused on implementing the specific goals or activities of the state’s Act

Early plan, which allowed grantees to integrate elements of the plan in state systems. Later rounds provided opportunities to advance the system-wide commitment, reinvigorate the Act Early plan, and bring together groups to identify issues and resources to achieve a common goal.

Qualitative data from the survey and environmental scan indicate that the grants provided opportunities to build systems-level relationships and connections on shared priorities around developmental monitoring and early identification. As one grantee stated, the establishment of partnerships and activities to integrate LTSAE into state systems resulted in “building of a culture of developmental monitoring.” The grants allowed many grantees to embed LTSAE materials and developmental monitoring into state policy and procedures. Highlighted below are two examples: Montana’s incorporation of LTSAE and rebranding Part C Early Intervention Program and Virginia’s Act Early Team involvement with the Virginia Department of Health’s Developmental Screening Initiative. In fact, many grantees continue to build upon partnerships and foster coordination around the shared priorities of developmental monitoring and early identification in their post-grant sustainability activities.



Impact Points	Areas of Improvement	# of States Reporting Improvement
Formalizing Developmental Monitoring & Early Identification as a Priority	Integration of system uses of LTSAE information/materials in some of their regular activities	All 26 states
	A policy or practice has been changed or created to conduct developmental monitoring and screening	22 out of 25
	A policy or practice has been changed or created for better coordination of early identification and early intervention services	19 out of 23

Grantee Spotlights: Formalizing Developmental Monitoring and Early Identification as a Priority

Montana (via University of Montana, 2014-16 and 2016-19 cohorts): Focusing Statewide Activities	
The Need	In 2014, Montana needed a comprehensive, collaborative, statewide plan that outlined evaluation, diagnosis, and services for children with ASD/DD. Montana also identified the need to better align existing resources to create a consistent approach to navigating the system of care. Many Montana families live in very small communities, which requires multiple systems to function together to create family-centered, cross-disciplinary approaches to diagnose, treat, and manage ASD/DD.
Strategies to Address the Need	<ul style="list-style-type: none"> ✓ Develop a statewide ASD/DD plan ✓ Established the framework for a Montana ASD toolkit and roadmap for parents, child care providers, educators, early intervention providers, and health practitioners ✓ Engaged in a variety of social media, web-based, and print dissemination initiatives to raise awareness of issues, resources, and available services
Implementation Activities	<ul style="list-style-type: none"> ✓ Convened a statewide Act Early team to develop a plan to guide policy and practice discussions that engaged more than 50 stakeholders from state early childhood and early intervention programs, university centers, public health services, community service providers, family members, policy makers, health care, and other educational professionals ✓ Developed a state autism plan that represented a consensus standard to assist in decision making and to demonstrate a level of key stakeholder agreement on issues related to ASD/DD ✓ Launched the Montana Autism Center website, which includes Montana-specific resources, a roadmap and toolkit of resources for parents and providers, and lends credibility to Montana's efforts and the national resources integrated ✓ Sought many opportunities to engage partners and stakeholders in the process of developing the state plan and website. As a result, a representative of the Act Early team was invited to sit on the state's Best Beginnings Advisory Council. The Council is a Governor-appointed board that advises state government on early childhood policy.
Impact	<ul style="list-style-type: none"> ✓ Enabled relationship building across agencies, organizations, and other interested parties, which resulted in a long-needed mechanism to bring community expertise together around a common issue, as well as opportunities to expand training and information dissemination initiatives ✓ Brought together several stakeholders engaging in parallel activities on a shared priority issue, which ensured alignment of resources and reduced duplication of efforts ✓ Provided a unifying message and direction for the state team around developmental monitoring and early identification. For example, Montana's Part C agency renamed itself "Montana Milestones Part C Intervention" to capitalize on the LTSAE milestones concept. ✓ Institutionalized the Act Early efforts into the state early childhood system by serving on the Best Beginnings Advisory Council
Project Contact	Dr. Martin Blair martin.blair@umontana.edu
Relevant Resources	Montana Autism Center

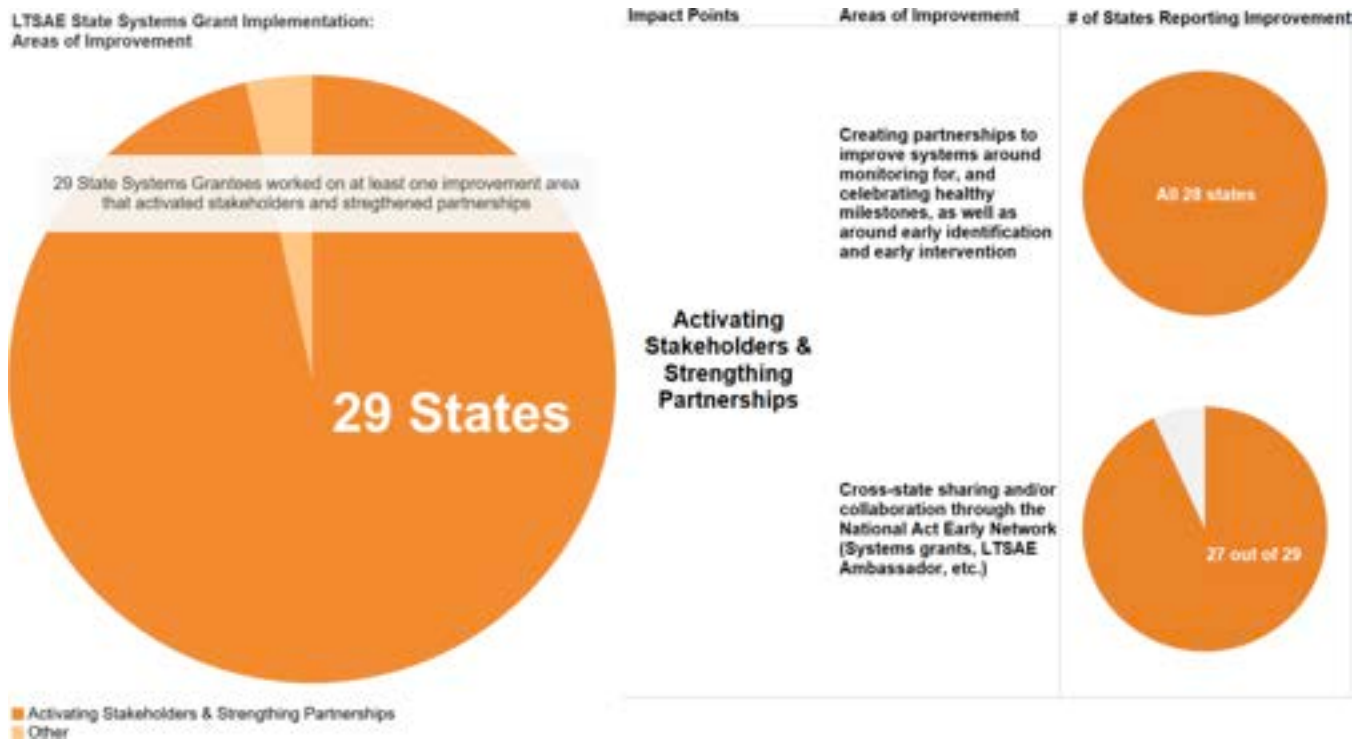
**Virginia (via Virginia Commonwealth University, 2013 cohort):
Prioritizing Actions for Early Identification - Capitalizing on Opportunities through Shared Strategies**

The Need	Virginia's Act Early team was formed in 2010 during the initial Act Early Summits. The team developed an Act Early plan, with priority placed on activities that would increase public awareness of the early signs of ASD. In the following year, the Act Early team refined the plan to focus on collaboration with medical professionals, strengthening connections to other early childhood partners as primary referral sources, and developing a more coordinated plan for early identification and diagnosis of young children (under age 3) with ASD.
Strategies to Address the Need	Put in place strategic elements to improve screening and diagnosis of young children with ASD in Virginia so that they could be identified and evaluated in a timely manner.
Implementation Activities	<ul style="list-style-type: none"> ✓ Expanded Act Early team membership to 26 members who represented state agencies, advocacy groups, families, and medical professionals ✓ Convened the team to conduct a strategic planning process to improve the early identification of children with ASD and support for their families ✓ Using the appreciative Inquiry model, the team identified priority areas for action, areas where collaboration could occur, and areas of concern. ✓ Developed a strategic planning document that provided direction for Virginia to address priorities collaboratively ✓ Used the planning document to develop Virginia's application for a Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB) Autism State Implementation Grant to implement changes identified in the plan
Impact	<ul style="list-style-type: none"> ✓ Convening the Act Early team provided stakeholders an avenue to openly discuss the current state of early identification, screening, and diagnosis of ASD in Virginia ✓ Reached a consensus that having a commonly endorsed state plan is necessary to address early identification, screening, and diagnosis of young children in Virginia ✓ Allowed Virginia to be more strategic surrounding early screening, identification and diagnosis of ASD, and capitalize on the opportunity to submit the state's application for the MCHB Autism State Implementation Grant ✓ Received funding for the Autism State Implementation Grant (ASD Early Step) and implemented systems improvements, notably in early identification and expanded diagnostic capability, in three communities in the state ✓ Through ASD Early Step, trained interdisciplinary diagnostic teams in two localities in Virginia, early care and education providers in three localities, and early intervention teams throughout Virginia to administer the Modified Checklist for Autism in Toddlers (M-CHAT) as part of their practice. ✓ Collaborators from Virginia's Act Early Team are now involved in the Virginia Department of Health's Developmental Screening Initiative to improve Virginia's screening rates.
Project Contact	✓ Deana Buck dmbuck@vcu.edu
Relevant Resources	<p>Autism Spectrum Disorder Screening and Diagnosis: Early Systematic Training in Effective Practices (ASD Early STEP)</p> <p>AMCHP-Virginia Addressing Gaps in ASD-DD Diagnosis</p>

Impact Point: Engaging Stakeholders. Strengthening Partnerships.

Figure 3 highlights a second major impact point of the LTSAE state systems grant: engaging stakeholders and strengthening partnerships. 29 states worked on at least one of the two improvement areas related to this impact point. The majority of states that worked on the following areas of improvement agreed that it made a positive impact on:

- Creating partnerships to improve systems related to monitoring and celebrating healthy milestones as well as those related to early identification and early intervention (n: 26 out of 26);
- Cross-state sharing and/or collaboration through the National Act Early Network (n: 27 out of 29).



Comprehensive collaborations are key solutions to advancing the goals of LTSAE State Systems Grantees. Identifying LTSAE state team needs, engaging diverse stakeholders, and strengthening and fostering new partnerships enabled state teams to advance their project objectives. Targeted and consistent approaches to engage stakeholders across diverse settings—representing families, physicians, early childhood care providers, community organizations, academic centers, state departments, and legislators—enhanced statewide coordination of care, increased inter- and intra-sector collaboration, and strengthened workforce capacity. State teams' comprehensive collaborative efforts led to the development of priorities, including integrated statewide visions, messaging, and LTSAE tools.

Grantee Spotlights: Engaging Stakeholders. Strengthening Partnerships.

Mississippi (via University of Southern Mississippi, 2011 cohort): Statewide Coordination Parents and professionals working together to promote early identification for young children with ASD	
The Need	Increase the identification of children with ASD through routine screening statewide to screen young children at an earlier age and connect families to early intervention sooner.
Strategies to Address the Need	<ul style="list-style-type: none"> ✓ Increased early childhood educators' awareness of ASD and understanding of how to provide developmental screenings, for example using the M-CHAT ✓ Disseminated <i>Learn the Signs. Act Early.</i> campaign materials to the Cool Kids Program, Mississippi's Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), and promote the M-CHAT as an additional screening tool for the program.
Targeted Partnerships	<ul style="list-style-type: none"> ✓ Faith-based/community organizations ✓ Parents and families ✓ Early childhood educators ✓ Early childhood intervention stakeholders ✓ Healthcare professionals ✓ Public health professionals
Implementation Activities	<ul style="list-style-type: none"> ✓ Provided training to early childhood educators and healthcare professionals ✓ Provided technical assistance to model practices in each of Mississippi's health districts ✓ Compiled list of recognized programs across the state that provide diagnostic evaluation services
Impact	<p>Significant improvements in:</p> <ul style="list-style-type: none"> ✓ Capacity building for early identification of children with ASD/DD through professional development for early childhood educators. Over 2,000 early childhood educators attended <i>Follow Me: Monitoring Development in Early Childhood</i>, a two-hour training presented throughout the state ✓ Development of on-site mentoring programs that demonstrate how to implement monitoring programs in infant and toddler classrooms to provide LTSAE materials and support for teachers ✓ Support from the Mississippi Department of Human Services to provide a comprehensive training and developmental screening kit for 247 childcare centers throughout Mississippi ✓ Collaboration and information sharing with the University of Mississippi Medical Center and Mississippi Thrive (recipients of a 2017 HRSA grant) to support policy development and continued education on developmental screening for early childhood educators and medical professionals.
Project Contact	Alicia Westbrook alicia.westbrook@usm.edu
Resources	MAAC PowerPoint Presentation: http://bit.ly/2yYbWuB

**Nebraska (via University of Nebraska Medical Center, 2012-2013 cohort): Multi-sector Collaboration
Achieving Programmatic Goals through Strengthened Teamwork**

The Need	Enhance coordination and collaboration between The ASD Network, (the statewide system of educational supports and services for individuals with ASD) and the Early Development Network (Nebraska's early childhood and early intervention services program)
Strategies to Address the Need	<ul style="list-style-type: none"> ✓ Coordinated with the Early Childhood Training Center's Early Learning Connection (ELC) Partnerships across the state ✓ Increased state legislators' awareness on issues related to ASD services and needs in Nebraska ✓ Strengthened partnerships and communication between Nebraska Act Early state team members
Targeted Partnerships	<ul style="list-style-type: none"> ✓ The Nebraska Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Training Program ✓ The Nebraska ASD Network/State Department of Education ✓ Autism Center of Nebraska ✓ Early childhood and early intervention stakeholders ✓ Nebraska Department of Health and Human Services ✓ State legislature/policymakers ✓ Autism Society of Nebraska
Implementation Activities	<ul style="list-style-type: none"> ✓ The State Autism Collaborative/Nebraska LEND program provided financial support to the training efforts of the Nebraska ASD Network through an annual Autism Diagnostic Observation Schedule (ADOS-2) training to eight to 12 professionals from the ASD Network and the Early Development Network, as well as to 30 young professionals and students ✓ Collaborated with the seven regional Early Learning Connection Partnerships to customize and disseminate information about the state team and LTSAE campaign ✓ Worked with the ELC's statewide free access child care resource and referral hotline to incorporate LTSAE materials into their program ✓ Coordinated statewide series of awareness events
Impact	<p>Significant improvements in:</p> <ul style="list-style-type: none"> ✓ Capacity building for early identification of children with ASD/DD ✓ Capacity building for coordination of early education and early intervention services for children with ASD/DD ✓ Creating partnerships to improve systems related to monitoring for and celebrating healthy milestones ✓ Integration of system uses of LTSAE information/materials in the ASD Network's regular activities ✓ Better coordination of early identification and early intervention services linked to the creation of policies and practices ✓ Cross-state sharing and/or collaboration through the National Act Early Network (systems grants, LTSAE Ambassador, etc.)
Project Contact	Cynthia Ellis, MD cellis@unmc.edu
Relevant Resources	<p>ASD Motiongraphic Nebraska State Autism Collaborative Ambassador KMTV3 News Appearance</p>

Oklahoma (via University of Oklahoma Health Sciences Center, 2014-2016 cohort): Partner and Educate Leaders
 Community Screening Partner Network—Power of Partnership

<p>The Need</p>	<p>Increase the availability of developmental screening statewide and expand and support a diverse network of early childhood providers to screen young children and connect families to resources in the community</p>
<p>Strategies to Address the Need</p>	<ul style="list-style-type: none"> ✓ Expanded the Community Screening Partner (CSP) Network, a selected group of targeted individuals at an agency or organization who routinely conduct developmental screening and can easily incorporate screening specifically for autism. In addition, these agencies support families of young children and can promote developmental monitoring using LTSAE materials. ✓ Supported existing and future CSPs ✓ Tracked and reported screening and awareness activities statewide
<p>Targeted Partnerships</p>	<ul style="list-style-type: none"> ✓ Early childhood professionals <ul style="list-style-type: none"> ○ Southwest Oklahoma Community Action Group and Community Action Development Corporation Head Starts ○ Oklahoma Health Department Child Guidance Services ✓ Family and community partners <ul style="list-style-type: none"> ○ Oklahoma City Latino Community Development Agency ○ Sunbeam Family Services ○ Choctaw Nation
<p>Implementation Activities</p>	<ul style="list-style-type: none"> ✓ Identified potential partners ✓ Trained, supported, and provided materials to CSPs <ul style="list-style-type: none"> ○ Screening materials for CSPs ○ CSP screening manual and instruments to new CSP teams ○ Revised CSP screening manual updates for newly revised instruments ○ Additional screening instruments protocols as needed ○ Ongoing support for CSPs ○ Interactive multimedia training ✓ Fielded screening requests statewide and referred to CSPs ✓ Developed and distributed CSP survey for feedback regarding Early Access training, support, and input regarding barriers, challenges, and needs in implementing the screening model ✓ Promoted awareness of autism and developmental screening <ul style="list-style-type: none"> ○ Promote at Oklahoma Statewide Autism Conference ○ Promote statewide screening network using, media, website, and social media ✓ Created online CSP directory ✓ Tracked CSP screening activities
<p>Impact</p>	<p>Significant improvements in:</p> <ul style="list-style-type: none"> ✓ Creating partnerships to improve systems related to monitoring for and celebrating healthy milestones as well as those related to early identification and early intervention ✓ Policy/practice have changed or created to conduct developmental monitoring and screening ✓ Awareness of the importance of developmental monitoring ✓ Capacity building for early identification for children with ASD/DD
<p>Project Contact</p>	<p>Bonnie McBride bonnie-mcbride@ouhsc.edu</p>
<p>Relevant Resources</p>	<p>Community Screening Partners training agenda</p>

Impact Point: Training and Raising Awareness among Key Stakeholders

Figure 4 highlights the third major impact point of the LTSAE state systems grants: training and raising awareness among key stakeholders. 28 states worked on at least one of the two improvement areas related to this impact point. A vast majority of states that worked on the following areas of improvement agreed that the grant made a positive impact on:

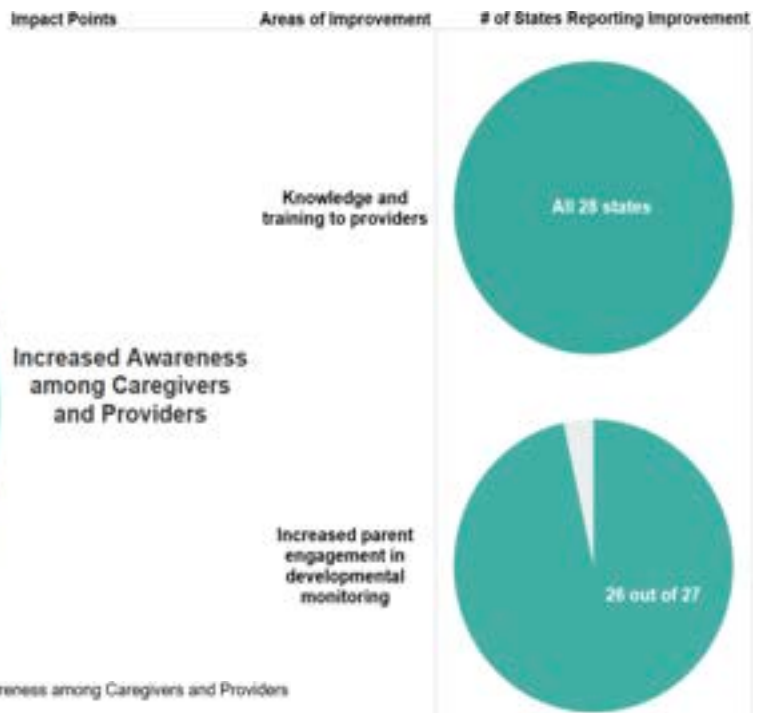
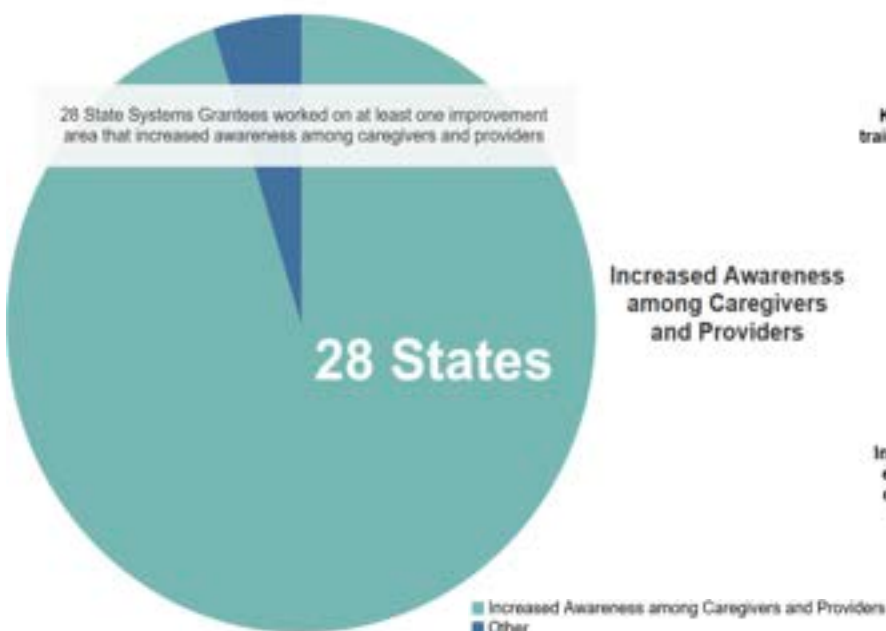
- Knowledge and training to providers (n: 28 out of 28)
- Increased parent engagement in developmental monitoring (n: 26 out of 27).

Most state teams' strategies included training and raising awareness as an essential impact point for achieving grant aims. These activities promoted the necessity of developmental monitoring and worked to build capacity among stakeholders to integrate the CDC's LTSAE developmental monitoring tools during regular interactions with children. Grantees selected an audience, which prioritized a variety of key stakeholders within the early childhood development system, whether early childhood providers (Head Start/Early Head Start, WIC, Home Visiting), Title V, physicians, libraries, hospitals, parents, university students studying child development, and departments of education. As a result, state teams implemented trainings and

campaigns to raise awareness using strategies that included cable TV programming, university curricula, online webinars and interactive modules, in-person trainings, and print resources such as toolkits and checklists.

Overall, this impact point is the one in which grantees reported they had the most immediate influence in achieving their program goals. Self-reported data from the grantee survey indicated that approximately 97 percent of grantees experienced increased awareness among key stakeholders of the importance of developmental monitoring and screening. State teams discussed the lessons learned in leveraging this impact point. In their discussions, they emphasized the importance of framing the message to key stakeholders and/or partners about integrating LTSAE materials in their day-to-day procedures as a complement to their work. In addition, grantees indicated that the CDC's Milestones tools (particularly the Milestones checklist, Milestones in Action, and the Milestones Tracker app) were the most useful of the LTSAE materials when working with partners and stakeholders. Moving forward, past and current state grantees are prioritizing training of early education and child care providers on how to use and integrate LTSAE screening materials within their regular processes.

LTSAE State Systems Grant Implementation: Areas of Improvement



Grantee Spotlights: Training and Raising Awareness among Key Stakeholders

California (via <i>The Regents of the University of California</i> , 2013 Cohort): Supporting the Use of LTSAE Materials in Home Visiting	
The Need	The 2007 California Legislative Blue Ribbon Commission on Autism Report addressed the need for early identification of ASD/DD, especially in underserved populations and communities.
Strategies to Address the Need	The California Home Visiting Program provides services to many children during their early developmental years. This program served as an opportune partner in improving access to information about developmental milestones and referral to evaluation services for California families with children. The California team distributed LTSAE materials, which were customized to meet the needs of the community, to the 21 counties implementing the home visiting program under the Department of Public Health.
Intended Audience	Home Visiting Staff
Implementation Activities	<ul style="list-style-type: none"> ✓ Provided an in-person training to home visiting staff and California Department of Public Health staff members during the 2013 California Home Visiting Summit. The training emphasized the importance of developmental guidance, screening, sharing concerns with caregivers, and referrals. <ul style="list-style-type: none"> ○ Each home visiting program received a tote bag filled with relevant LTSAE materials. Labels with the local referral agencies were customized for each home visiting program. ✓ To support the referral process for evaluation services, two tools were developed specifically for home visitors: (1) <i>The Roadmap for Helping Your Child Grow</i>, a document that identifies concerns for parents, can bring it their child's physician or referral agency and (2) <i>Early Identification and Developmental Screening for California's Children</i>, which outlines "next steps" for the home visitor after they have screened a child. ✓ To keep home visitors' knowledge up to date, the project team created a weekly eblast, <i>Home Visiting Connection</i>, to share news and information that benefits home visiting programs throughout the state. <p>Relevant Partners: California Home Visiting Program, local referral agencies, Early Head Start home visitors, and Part C home visitors</p>
Impact	<ul style="list-style-type: none"> ✓ Nearly 300 Home Visiting/California Department of Public Health staff, Early Head Start, and Part C home visitors received training. As a result, staff that used the LTSAE materials increased both their confidence and competence. ✓ Strengthened working relationships between LTSAE State System Grant team members ✓ 2000+ LTSAE materials were distributed
Project Contact	Robin Hansen rlhansen@ucdavis.edu
Relevant Resources	California Home Visiting Summit presentation Early Identification: Key Components

**New Mexico (via *The New Mexico Pediatric Society, 2016-2019 Cohort*):
The Red Envelope Project: Tools for Provider and Caregiver Engagement**

<p>The Need</p>	<p>According to the Annie E. Casey Foundation 2015 KIDS COUNT Data Book, New Mexico ranks 49th in the nation for children’s well-being. Ensuring that parents have appropriate expectations for their child’s behavior and that they have access to accurate information about raising young children was identified as one of the five protective factors that are needed to create healthy environments for optimal child development. This research underscores the need for early childhood professional community to work together to strengthen statewide systems that serve young children and their families by increasing parent/family engagement in the developmental monitoring of their young children.</p>
<p>Strategies to Address the Need</p>	<p>Increased parent engagement in developmental monitoring by disseminating newborn screening documents and customizing developmental/behavioral screening resources and LTSAE materials statewide. The providers that care for these infants were strongly encouraged to engage in newborn screening and developmental monitoring of the children in their care. New Mexico’s parent engagement strategies have focused on directly reaching new parents once they are discharged from their hospital birthing center to follow up with local primary care providers (PCPs).</p>
<p>Intended Audience</p>	<p>Health care professionals in hospital labor and delivery units and local pediatricians</p>
<p>Implementation Activities</p>	<ul style="list-style-type: none"> ✓ Recruited discharge nurses as champions of the Red Envelope Project to oversee the dissemination of newborn screening, follow-up screenings, and LTSAE/developmental materials, which were given to new parents in a red envelope ✓ Built capacity among health care professionals in the labor and delivery units on the importance of newborn screenings, follow-up screenings, developmental monitoring, and developmental/behavioral screening ✓ Established partnerships with key PCP offices to facilitate the follow-up of the newborn screenings and to promote developmental monitoring to new parents via the LTSAE materials and the Development Trackers ✓ Investigated effective measures to evaluate the impact of the Red Envelope Project in select pilot sites and tailor as needed <p>Relevant partners: New Mexico Department of Health (NM DOH), New Mexico Pediatric Society, labor and delivery hospital staff, early intervention and home visiting programs.</p>
<p>Impact</p>	<ul style="list-style-type: none"> ✓ After an 18-month pilot phase, the NM DOH rolled out a statewide effort to provide red envelopes and accompanying materials to all 33 hospitals in the state with birthing centers. Key locations with established partnerships with PCPs were targeted for community follow up. Pediatricians statewide reported that parents attended appointments with their red envelopes. The DOH designated a specific coordinator to follow up on referrals and the efficiency of the process has improved. ✓ The business development offices of metropolitan Albuquerque hospitals promote the Red Envelope Project since the vast majority of births occur in the metropolitan area. A priority is to follow up with Neonatal Intensive Care Unit (NICU) families who live in rural areas after their discharge from the hospital. ✓ To date, approximately 8,000 red envelopes have been disseminated.
<p>Project Contact</p>	<p>Nancy Lewis nancylewisslp@comcast.net</p>
<p>Relevant Resources</p>	<p>Development Tracker Card</p>

**Massachusetts (via *The University of Massachusetts Medical School, 2016-2019 Cohort*):
1, 2, 3, Grow! YouTube and Cable TV Series**

<p>The Need</p>	<p>Massachusetts is a geographically small but densely populated state with 6.9 million residents. Of the population, an estimated 16 percent of residents were born outside of the U.S. and 21.9 percent of residents older than age five speak a language other than English at home. Focus groups conducted with families revealed cultural barriers related to families' <i>not understanding</i> the importance of developmental concerns and the need to respond/act early when delays or concerns are identified. Many families feared that expressing concerns and/or taking action would result in being excluded from their communities.</p>
<p>Strategy to Address the Need</p>	<p>Developed and broadcasted a program about early childhood development for families of young children in eight languages on cable television stations across the state and on YouTube. The program hosts, physicians, and parents of young children represented the languages and cultures of their audiences: English, Spanish, Arabic, Chinese, Haitian-Creole, Portuguese, and Vietnamese. There was also a show in English focused on African-American cultural concerns. The shows were promoted, aired, and archived on multiple online platforms and educated families from diverse cultures about (1) healthy developmental milestones and (2) what to do about red flags or a potential concern in young children. A follow-up project of three animated videos and a discussion guide were also published.</p>
<p>Intended Audience</p>	<p>All community members, specifically parents and caregivers, with a focus on those of diverse racial, cultural, economic, and geographic backgrounds</p>
<p>Implementation Activities</p>	<ul style="list-style-type: none"> ✓ Developed, reviewed, and evaluated culturally and linguistically competent content for cable access TV and YouTube 30-minute shows “1, 2, 3, Grow!: A Program About Your Child’s Development” in eight languages ✓ Recruited Boston Neighborhood Network Television for tapings, interviewed panelists and show hosts, trained hosts, and rehearsed shows ✓ Translated all written materials into seven languages for use on air and for dissemination to families through online downloads and mailings ✓ Promoted successful YouTube and cable TV launch via multiple strategies/methods, coordinated with TV access networks across the state, and prepared websites for program uploads and translations ✓ Created three short videos and a discussion guide, “1, 2, 3, Grow! Animated Caregiver Stories,” using interviews from multicultural families in English ✓ Conducted a multicultural research evaluation of lessons learned in the “1, 2, 3, Grow!” project for journal publication <p>Relevant partners: Massachusetts Act Early state team members, cable television stations, ethnically and culturally diverse families, provider organizations, state agencies, Massachusetts Autism Commission, Massachusetts Executive Office of Health & Human Services</p>
<p>Impact</p>	<ul style="list-style-type: none"> ✓ More than 3,600 views of cable and YouTube shows during launch week ✓ Creation of a dedicated webpage of the “1, 2, 3, Grow!” video series on the UMass Medical School Shriver Center website, as well as the Commonwealth of Massachusetts website ✓ Engaged viewers beyond Massachusetts (including other U.S. states, Canada, and other countries) ✓ More formal evaluation forthcoming
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<p>Relevant Resources</p>	<p>“1, 2, 3, Grow!” one-minute video trailer</p>

Challenges and Lessons Learned

Common challenges reported by states in implementing and sustaining grant activities included time constraints, budget limitations, and staff turnover. For example, some states reported experiencing low levels of community readiness, endorsement by providers, and buy-in for LTSAE; these factors underscored the need for continuous outreach and policy implementation. Embedding developmental monitoring and screening at a systematic level can be an arduous process due to the challenges of merging separate systems with separate funding streams, coordinating the work of grantees to optimize efficiency, and overcoming the difficulty of linking families to support in localities. Examples of current initiatives underway to prioritize coordination of early intervention services focus on embedding LTSAE materials into systems such as childcare, WIC, library systems, early intervention, and home visiting programs. Implementing a systematic process for offering ASD screening using the Modified Checklist for Autism in Toddlers, Revised with Follow up (MCHAT-R/F) tool is another example of how grantees are striving to standardize processes.

Another significant barrier to systems change is finding the means for sustained and sufficient financial support. Ten (states mentioned that their AMCHP State Systems grant was utilized to kickstart writing grant proposals in order to secure additional funding. Other states noted that they needed to leverage other funding, and to be flexible with their efforts to adapt to opportunities that emerged and integrate LTSAE and the state system grant work into other programs and areas.

As demonstrated in the previous state examples, Act Early state teams, as well as strong community collaborations, were critical for ensuring sustainability for grant activities. Parent partners, and family engagement in particular, were deemed essential to the success of the work. The grantees stated that building partnerships and relationships, although time consuming, is a critical component to the success of systems change. One grantee commented on the “power in convening with a purpose,” and expressed that the state systems grants provided that opportunity to develop a shared agenda and create and maintain relationships that are key to sustaining efforts.

Conclusion

The survey and environmental scan revealed a wealth of information on outcomes, impact, and lessons learned from the entire eight years of the LTSAE State Systems grant program. Overall, the grant program was successful in building the capacity of states and jurisdictions to strengthen state and community systems to provide early identification and coordinate services for children with ASD/DD. This issue brief provides insight into the key strategies and impact points that contributed to sustainable improvements and changes once the grants ended. Strategies include making formalized developmental monitoring and early identification a priority, activating stakeholders and strengthening partnerships, and increasing awareness among caregivers and providers. Although approaches may differ across states and organizational structures, they can be adapted and replicated to aid state systems in increasing developmental monitoring and screening and improving approaches to meet the service needs for children with ASD/DD and their families.

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