



Improving State Systems for Parent-Engaged Developmental Monitoring

*A Review of Eight Years of State
System-Level Grantee Work*

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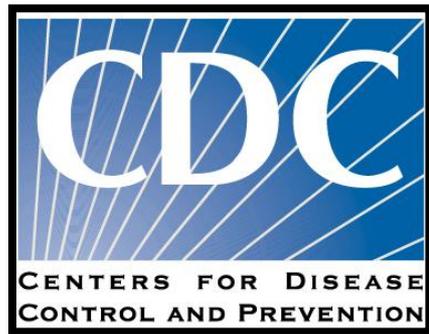
AMCHP is national resource, partner, and advocate for state public health leaders and others **working to improve the health of women, children, youth and families, including those with special health care needs.**

Learning Objectives

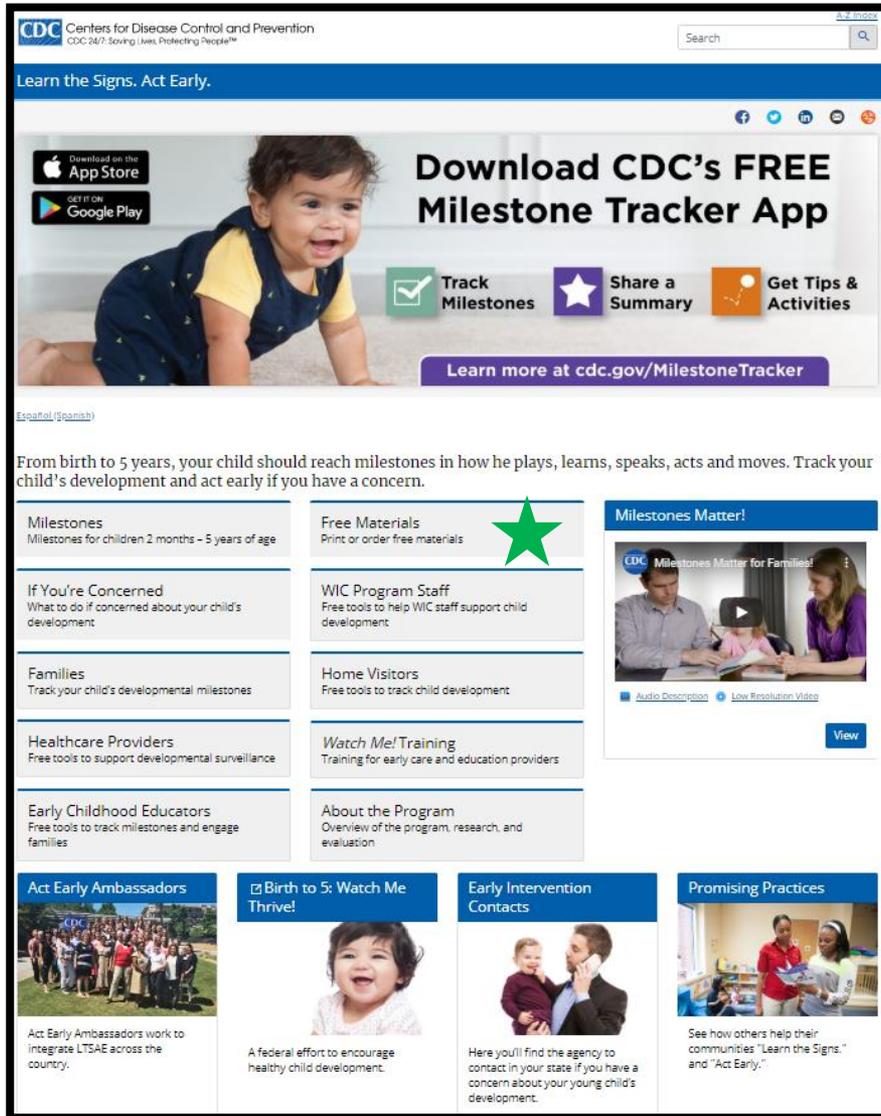
- ✓ Describe three impact points for improving states system capacity for
- ✓ Discuss practical examples of integration of the CDC's *Learn the Signs. Act Early.* (LTSAE) developmental monitoring tools into state systems
- ✓ Identify one opportunity to integrate LTSAE developmental monitoring materials into efforts for improving early childhood developmental monitoring and early intervention

Learn the Signs. Act Early. Initiative

Goal: To improve early identification of developmental delays and disabilities, including autism, by promoting developmental monitoring and screening so children and families can get the services and support they need



Developmental Monitoring Resources



The screenshot shows the CDC Act Early website. At the top, the CDC logo and tagline "Centers for Disease Control and Prevention" are visible. Below the logo is a search bar and the text "Learn the Signs. Act Early." A large banner features a smiling toddler and the text "Download CDC's FREE Milestone Tracker App". The banner includes icons for the App Store and Google Play, and three key features: "Track Milestones", "Share a Summary", and "Get Tips & Activities". A button below the banner says "Learn more at cdc.gov/MilestoneTracker".

Below the banner, there is a section titled "From birth to 5 years, your child should reach milestones in how he plays, learns, speaks, acts and moves. Track your child's development and act early if you have a concern." This section is divided into several categories:

- Milestones:** Milestones for children 2 months - 5 years of age.
- If You're Concerned:** What to do if concerned about your child's development.
- Families:** Track your child's developmental milestones.
- Healthcare Providers:** Free tools to support developmental surveillance.
- Early Childhood Educators:** Free tools to track milestones and engage families.
- Free Materials:** Print or order free materials (marked with a green star).
- WIC Program Staff:** Free tools to help WIC staff support child development.
- Home Visitors:** Free tools to track child development.
- Watch Me! Training:** Training for early care and education providers.
- About the Program:** Overview of the program, research, and evaluation.

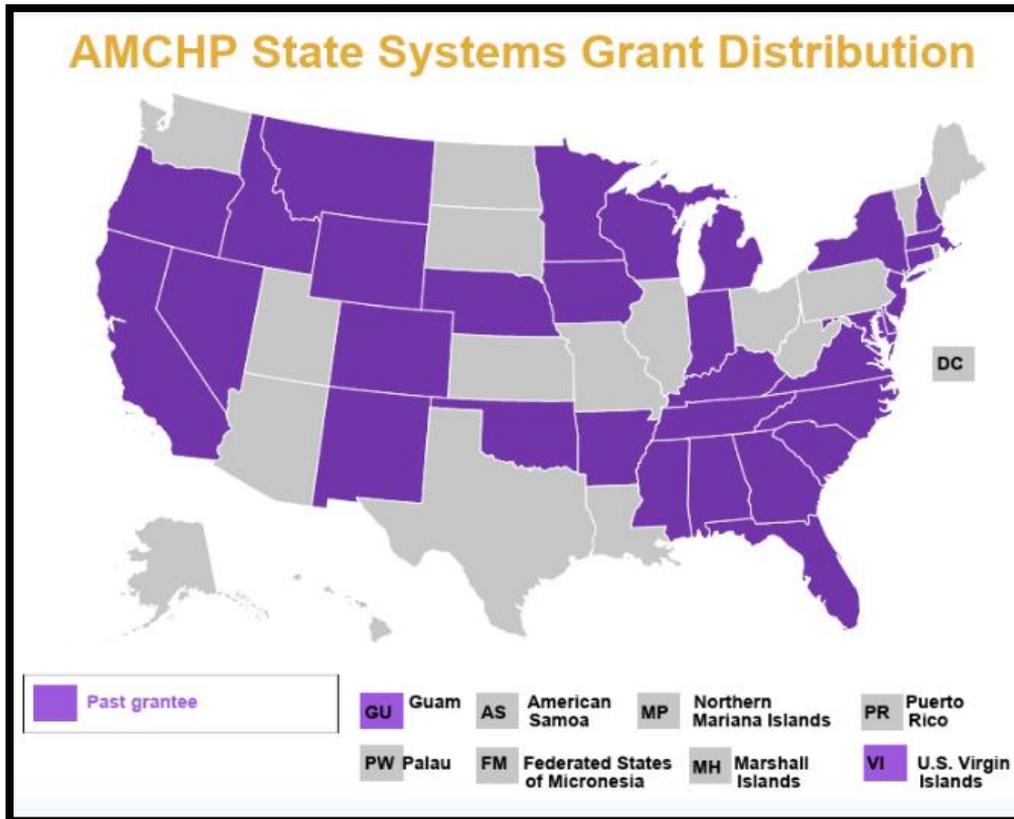
At the bottom, there are four featured sections:

- Act Early Ambassadors:** Act Early Ambassadors work to integrate LTS/AE across the country.
- Birth to 5: Watch Me Thrive!** A federal effort to encourage healthy child development.
- Early Intervention Contacts:** Here you'll find the agency to contact in your state if you have a concern about your young child's development.
- Promising Practices:** See how others help their communities "Learn the Signs" and "Act Early."

cdc.gov/ncbddd/actearly



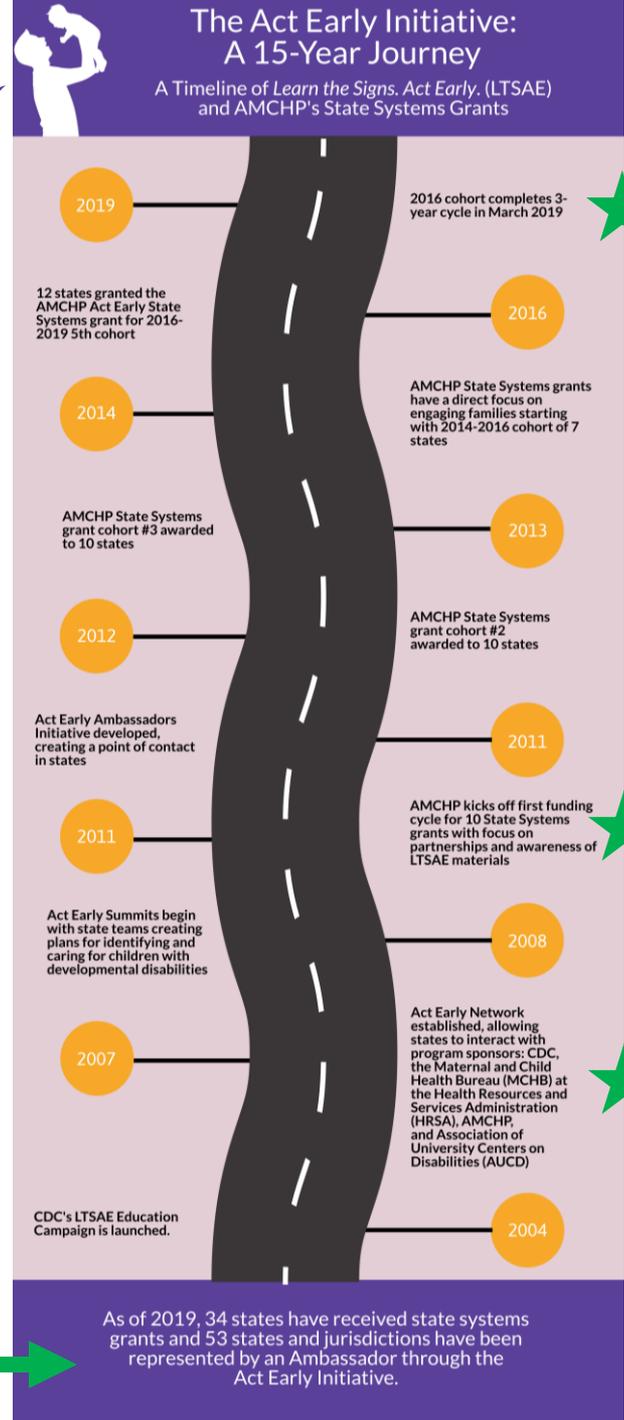
LTSAE State Systems Grants



Grants awarded to states/jurisdiction to:

- ✓ Strengthen state and community systems for early identification
- ✓ Improve coordination of early intervention services for children with signs of ASD/DD
- ✓ Ensure sustainability of efforts

The Act Early Initiative: A 15-year Journey



The Legacy of Eight Years of Work



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 DD. 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.

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.¹ 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.² These programs and services can

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.³

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

¹ Data & Statistics on Autism Spectrum Disorder (2018, April 6)
² Child Development (2019, February 6). Retrieved March 31, 2019.
³ Development Monitoring and Screening (2018, February 6). Retrieved March 31, 2019.
⁴ Autism Spectrum Disorder (2018, May 3). Retrieved March 31, 2019.

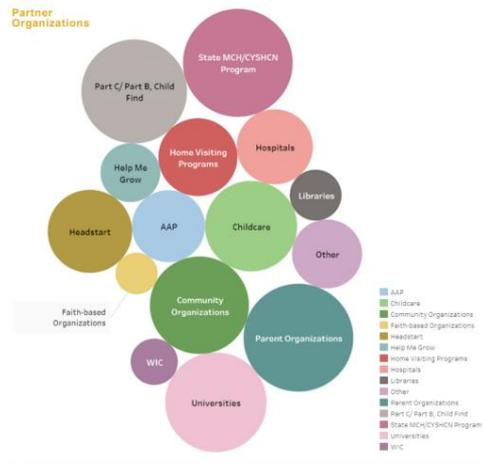


Figure 1 shows the myriad of partners that the LTSAE state systems grantees worked with to achieve their goals. Each specific organization or entity (e.g., hospitals) is represented by a bubble; the size of each bubble represents the number of grantees that it partnered with. For example, a larger number 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), The V MCH and CYSHCN programs, other public health human services departments, health systems, and nonprofit organizations.



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 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, a public-private partnership that provides a central hub of resources for parents and providers, and lends credibility to Montana's efforts to engage partners and stakeholders in the process of developing a shared plan and direction for the state team around developmental monitoring. For example, Montana's Part C agency renamed itself "Intervention" to capitalize on the LTSAE milestones concept. 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, a public-private partnership that provides a central hub of resources for parents and providers, and lends credibility to Montana's efforts to engage partners and stakeholders in the process of developing a shared plan and direction for the state team around developmental monitoring. For example, Montana's Part C agency renamed itself "Intervention" to capitalize on the LTSAE milestones concept.

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

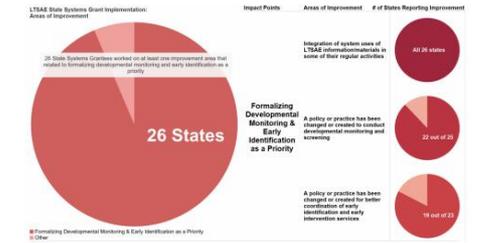
Figure 2 highlights the first of the three major impact points of the LTSAE state systems grant. 26 states worked on at least one improvement area related to formalizing developmental monitoring and early identification as a priority. The majority of states that worked on these areas agreed that the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



Survey Outcomes



94% of grantees felt that they **met their grant objectives**



Over 90% of grantees reported **improved provider knowledge and training** on the importance of developmental monitoring and screening

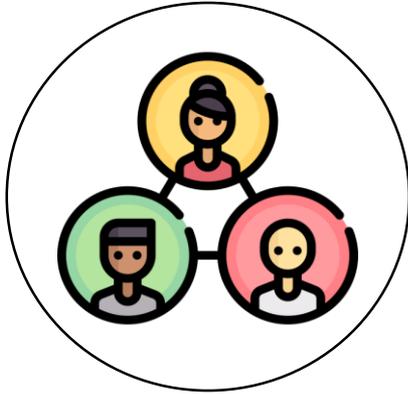


82% of grantees reported that the grant **helped create, strengthen, and/or sustain partnerships**

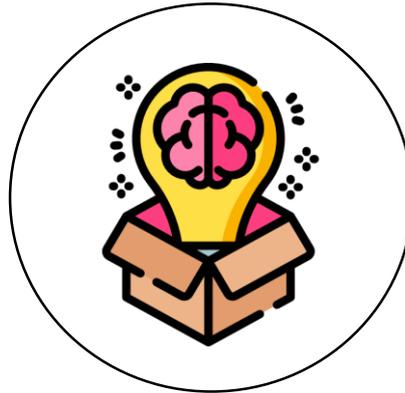


94% of grantees believed their grant-related efforts remained **sustainable or somewhat sustainable**

Findings: Three Impact Points



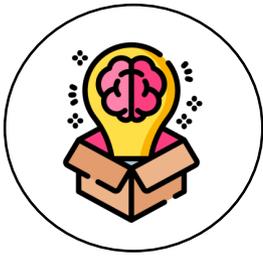
Activated stakeholders and strengthened partnerships



Increased awareness among caregivers and providers on the importance of developmental monitoring and early identification



Formalized developmental monitoring and early identification as a priority



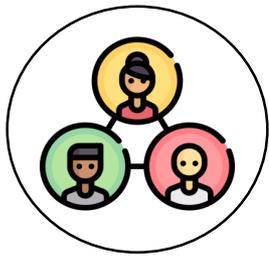
Increased awareness among caregivers & providers

Abridged Case Study: Massachusetts Act Early Team

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 YouTube

The shows 1) educated families about healthy developmental milestones based on the CDC's LTSAE materials and 2) provided instructions on what to do about red flags or potential concerns in young children.

More than 3,600 views of cable and YouTube shows during launch week; more formal evaluation forthcoming



Activate Stakeholders & Strengthen Partnerships

Abridged Case Study: Oklahoma Act Early Team

Expanded the Community Screening Partner 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.

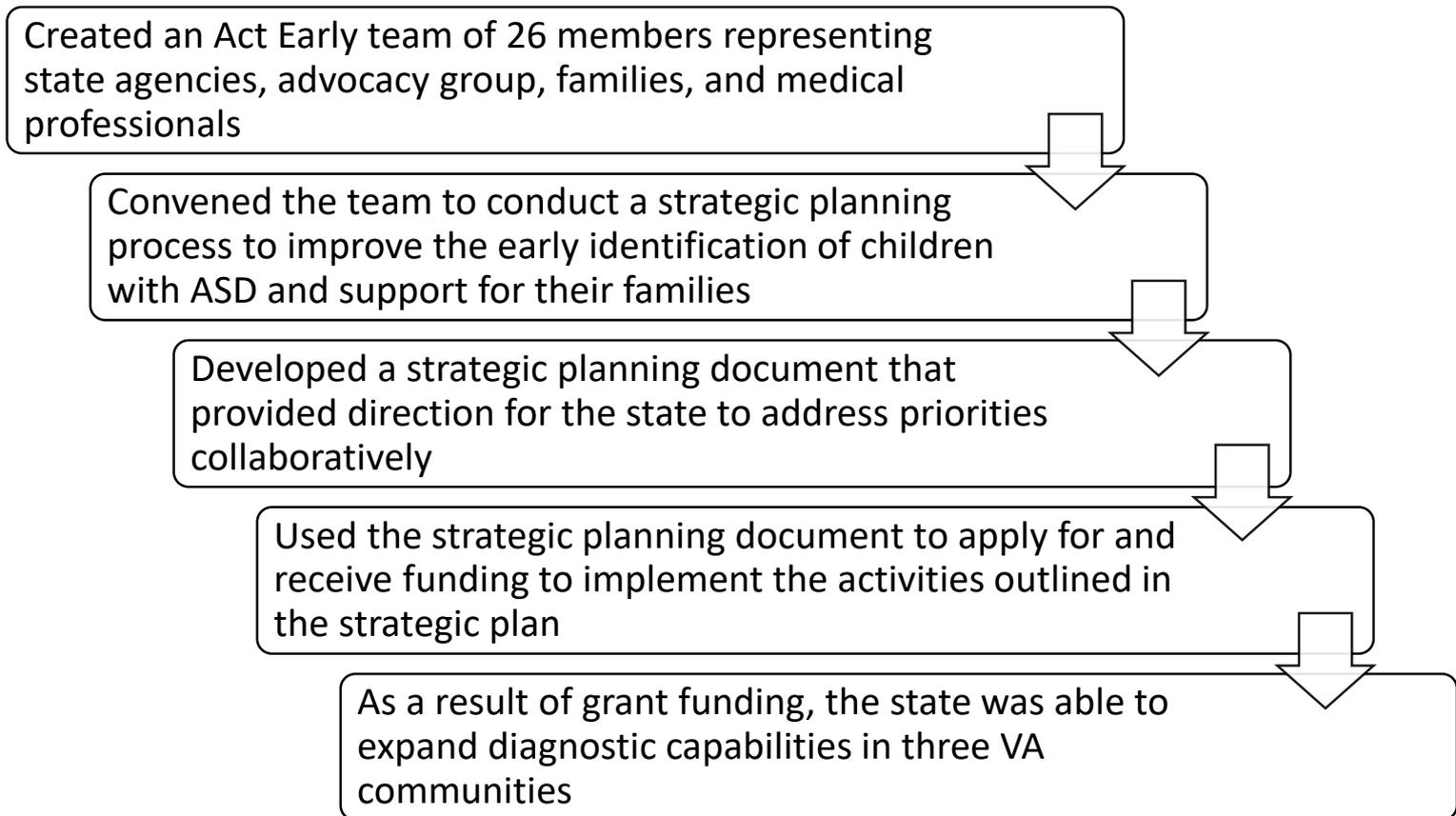
Trained, supported, and provided materials to Community Screening Partners

The expanded CSP network resulted in creation or changes in policies and practices across member's organizations related to conducting developmental monitoring and screening



Formalized developmental monitoring and early identification as a priority

Abridged Case Study: Virginia Act Early Team



In Conclusion...

- ✓ The LTSAE State Systems Grants were a successful mechanism for strengthening state and community systems to provide early identification and coordinate services for children with ASD/DD
- ✓ Although approaches differ across states, they can be adapted and replicated to aid state systems in increasing developmental monitoring and screening for early identification

Resources to check out:

- ✓ Leverage the **freely available** LTSAE resources to sustainably integrate developmental monitoring within early childhood systems that already exist in your state (WIC, Head Start, Home Visiting, Health Systems, etc.)



- ✓ Check out the full interactive Legacy Product for case studies highlighting how several states achieved sustainable outcomes with a small amount of funding





Thank you!



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