Integrating Title V Data into Early Childhood Integrated Data Systems (ECIDS)

10th Annual Help Me Grow National Forum| Buffalo, NY
May 8, 2019 2:45-3:45PM EST | Room: Niagara

Presenter

Paige Bussanich, M.S.

pbussanich@amchp.org

Senior Program Manager
Children and Youth with
Special Health Care Needs

Ask me about:
- ✓ Children and Youth with Special Health Care Needs/Medical Complexity
- ✓ Autism and other Developmental Disabilities
- ✓ Early Childhood Data Integration
- ✓ Leadership Institute for CYSHCN Directors
- ✓ Systems of Care
- ✓ Developmental Monitoring & Screening
- ✓ Zika response

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Over the next hour…

- Who is AMCHP? What is Title V?

  ….**and why you should care**

- How AMCHP supports developmental screening efforts

  – Opportunities for data integration & sharing

- Q & A

- Activity: Creating your Data Story

- Session Evaluations

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Learning Objectives

1. Identify opportunities for cross-system collaboration between Title V & Help Me Grow Programs to support data integration.

2. Understand the role of data integration within a comprehensive system of services necessary for optimal early childhood development outcomes.

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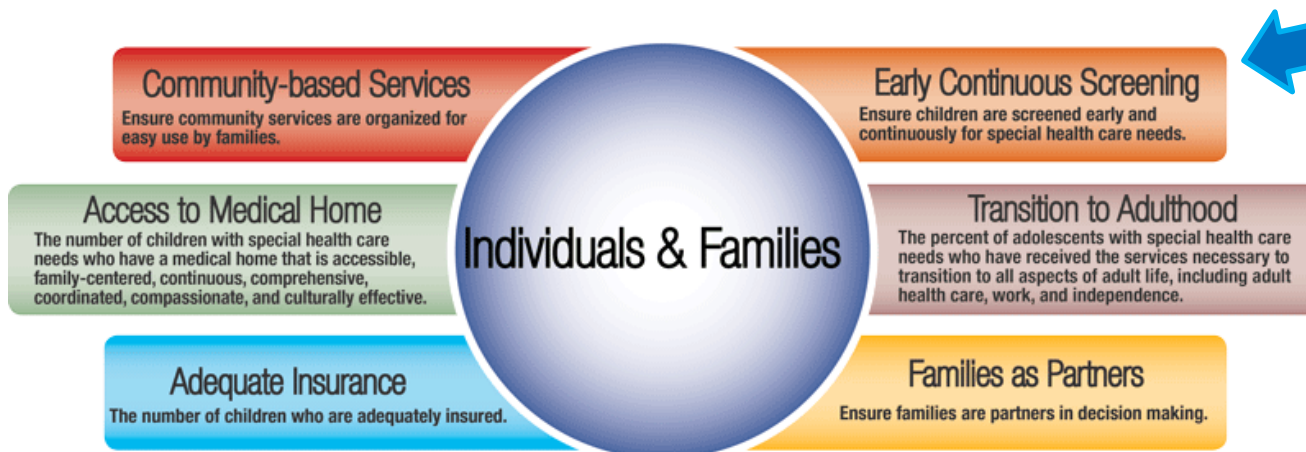
AMCHP

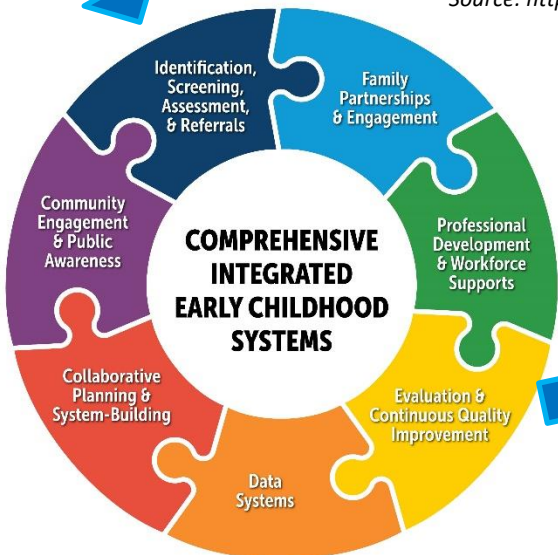# Screening is an important piece of early childhood services...

Linkage to appropriate, coordinated care and services for the child and family

All children reach their full potential

...and part of effective systems of care!

Source: https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

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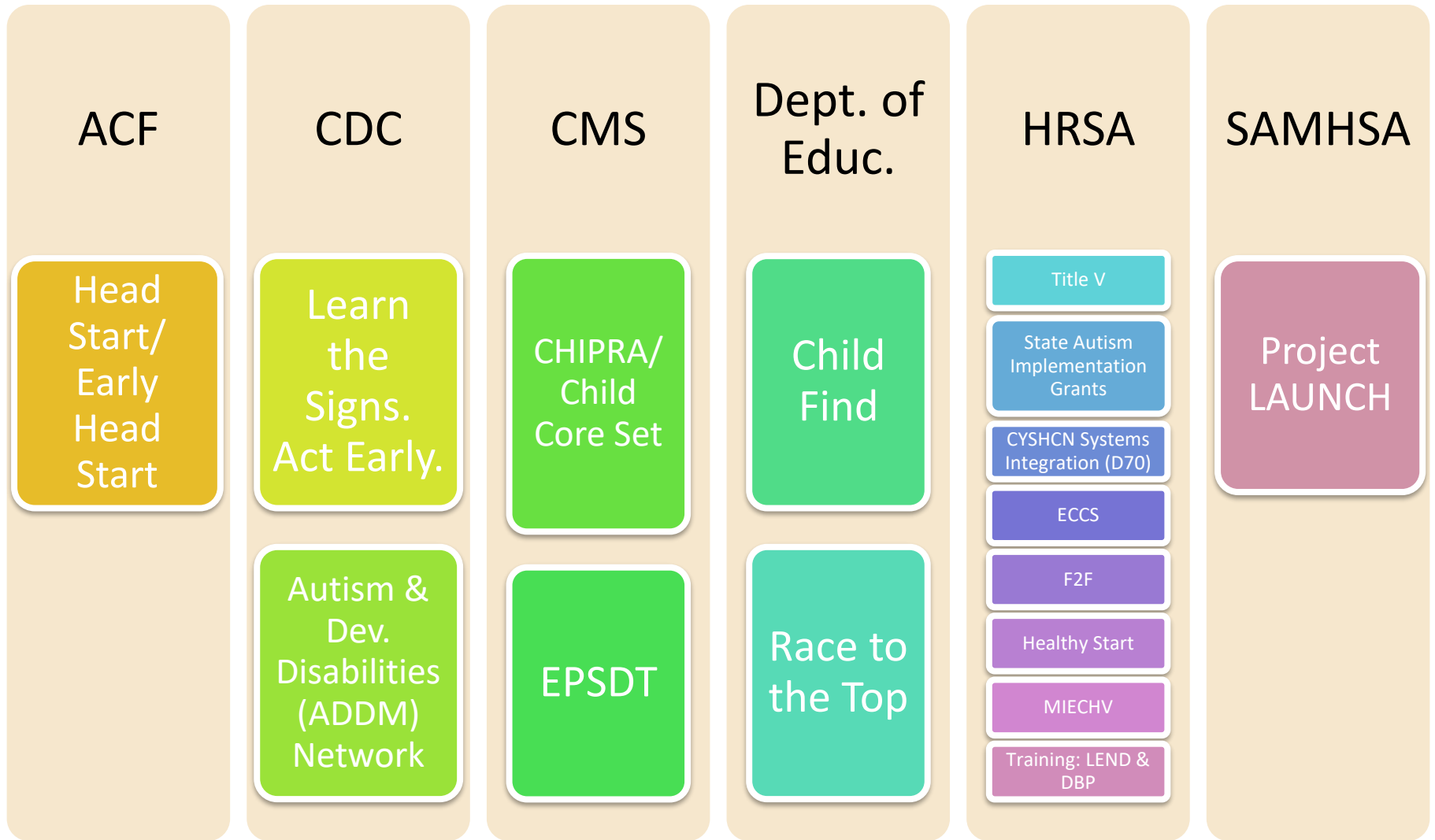

National Standards *for* **CYSHCN**

1	Identification, Screening, Assessment, and Referral
2	Eligibility and Enrollment in Health Coverage
3	Access to Care
4	Medical Home
5	Community-Based Services and Supports
6	Transition to Adulthood
7	Health Information Technology
8	Quality Assurance and Improvement

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Federal Landscape

ACF	CDC	CMS	Dept. of Educ.	HRSA	SAMHSA
Head Start/ Early Head Start	Learn the Signs. Act Early.	CHIPRA/ Child Core Set	Child Find	Title V	Project LAUNCH
	Autism & Dev. Disabilities (ADDM) Network	EPSDT	Race to the Top	State Autism Implementation Grants	
				CYSHCN Systems Integration (D70)	
				ECCS	
				F2F	
				Healthy Start	
				MIECHV	
				Training: LEND & DBP	

Birth to Five: Watch Me Thrive!

National Organizations Landscape

AAP	AMCHP	AUCD	NASHP	Help Me Grow National Center	Nat'l IP Network	National Quality Forum
Bright Futures	**National CYSHCN Standards** **Early Childhood Data Integration Toolkit**	**Six by Fifteen**	**Assuring Better Child Development (ABCD)**	**Help Me Grow**	**Improvement Partnerships**	**Endorsed Measures**
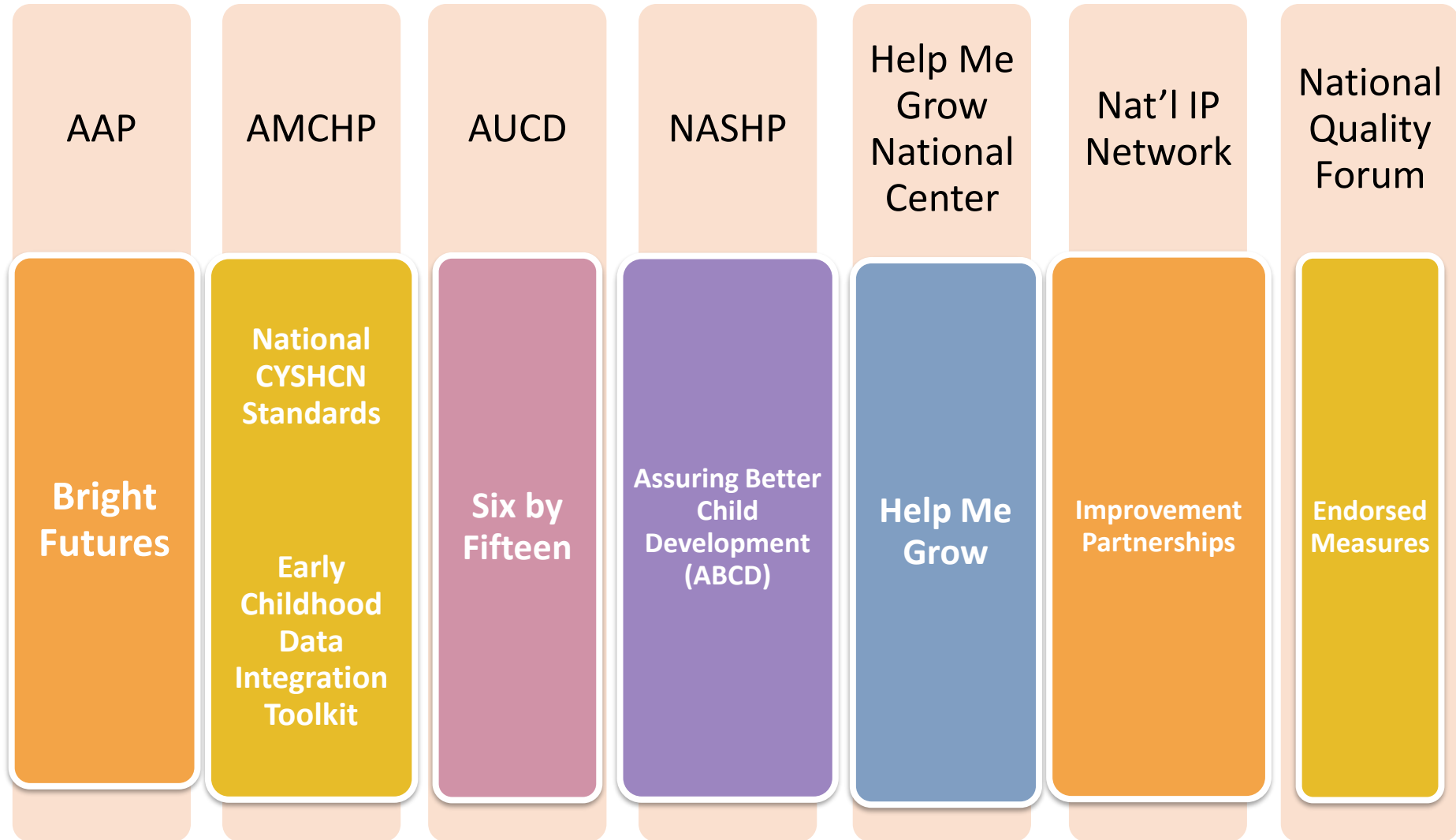
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Who is AMCHP?

- **Vision:** A nation that values and invests in the health and wellbeing of all women, children, youth, families, and communities so that they may thrive.

- **Mission:** Protect and promote the optimal health of women, children, youth, families, and communities.

- **Members:** Leaders/staff from state/territory health agencies and their partners who implement programs to improve the health of women, children, and families.

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What is Title V?

The nation's longest standing public health legislation focused solely on improving the health of all mothers and children, including children with special health care needs (*CSHCN*)

What is Title V?

The nation's longest standing public health legislation focused solely on improving the health of all mothers and children, including children with special health care needs (*CSHCN*)

Appropriates funds to states to:

- Ensure access to **quality health services**
- Promote the health of children by providing **preventive and primary care services**
- Provide and **promote family-centered, community-based, coordinated care** for children with special health care needs
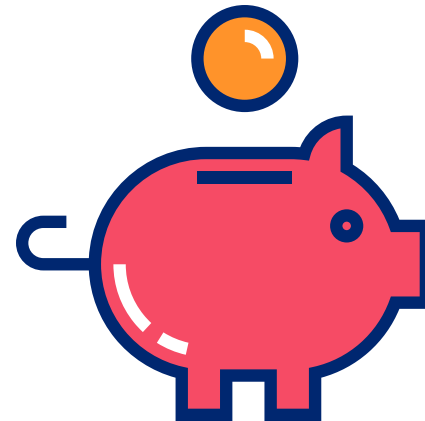
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Title V MCH Services Block Grants

Every 5 years, states conduct a needs assessment to prioritize MCH needs

Next stop: 2020!

Title V MCH Services Block Grants

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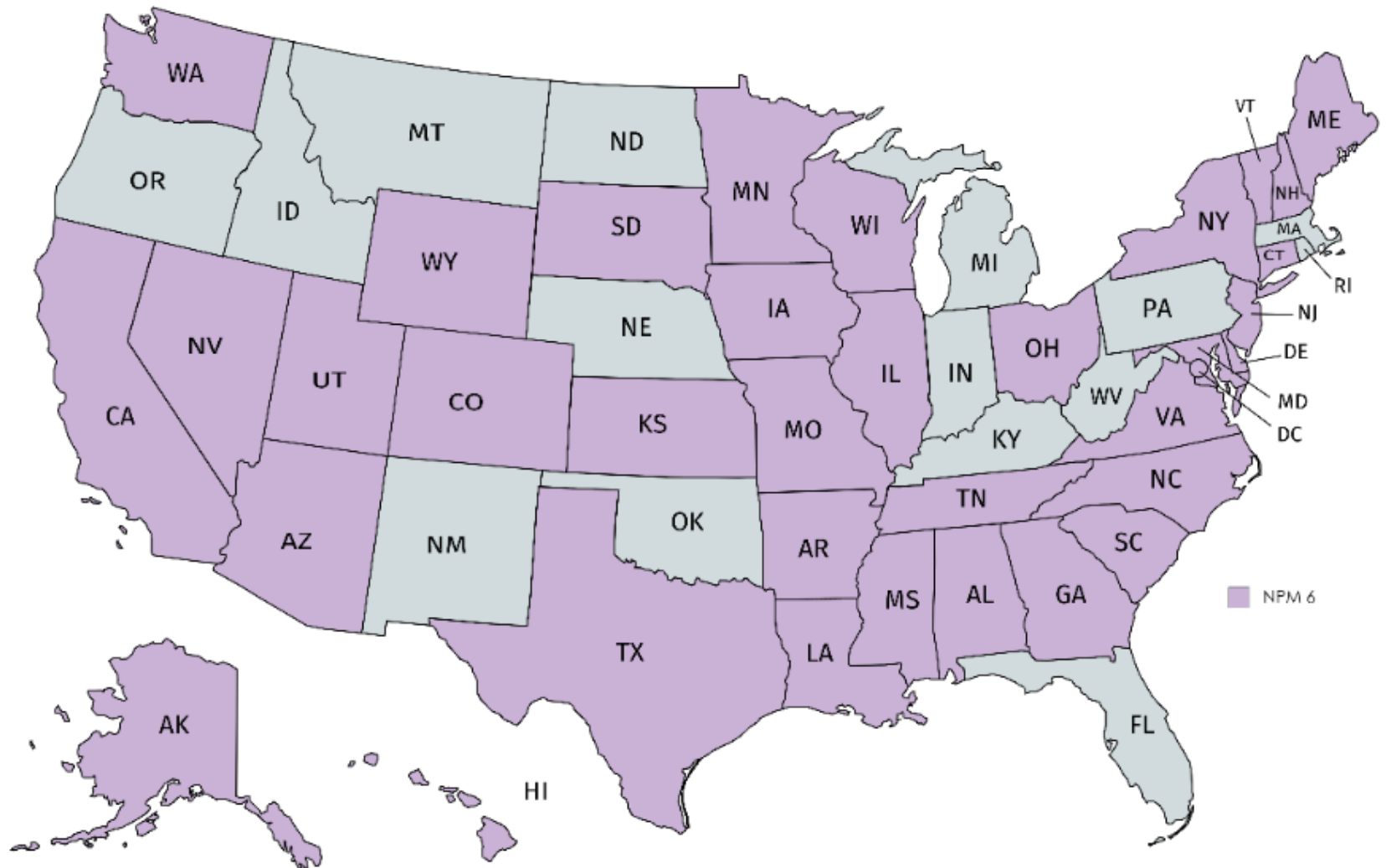Each year, states submit a block grant application outlining their strategic priorities for the year

Title V Performance Measurement Framework

National Outcome Measures

Population-level measures that reflect the ultimate health outcomes to be improved

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Title V Performance Measurement Framework

National Outcome Measures

Population-level measures that reflect the ultimate health outcomes to be improved

National Performance Measures

Process and/or program measures shown to affect the national outcome measures

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Title V Performance Measurement Framework

National Outcome Measures

Population-level measures that reflect the ultimate health outcomes to be improved

↑

National Performance Measures

Process and/or program measures shown to affect the national outcome measures

↑

Evidence-Based/Informed Strategy Measures

Accountability measures for improving quality and performance of state efforts related to the National Performance Measures

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Title V MCH Services Block Grants

Every 5 years, states conduct a needs assessment to prioritize MCH needs

Next stop: 2020!

Each year, states submit a block grant application outlining their strategic priorities for the year

With each block grant application, states select 5 National Performance Measures (out of 15), 3-5 state priority measures, and one or more state outcome measures

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National Performance Measure 6

Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year

National Performance Measure 6 Distribution

So, why does this matter to Help Me Grow?

HMG Affiliation

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NPM 6 & HMG Affiliate Alignment

Legend:
- NPM 6
- NPM 6 & HMG

Title V & HMG Affiliate Alignment
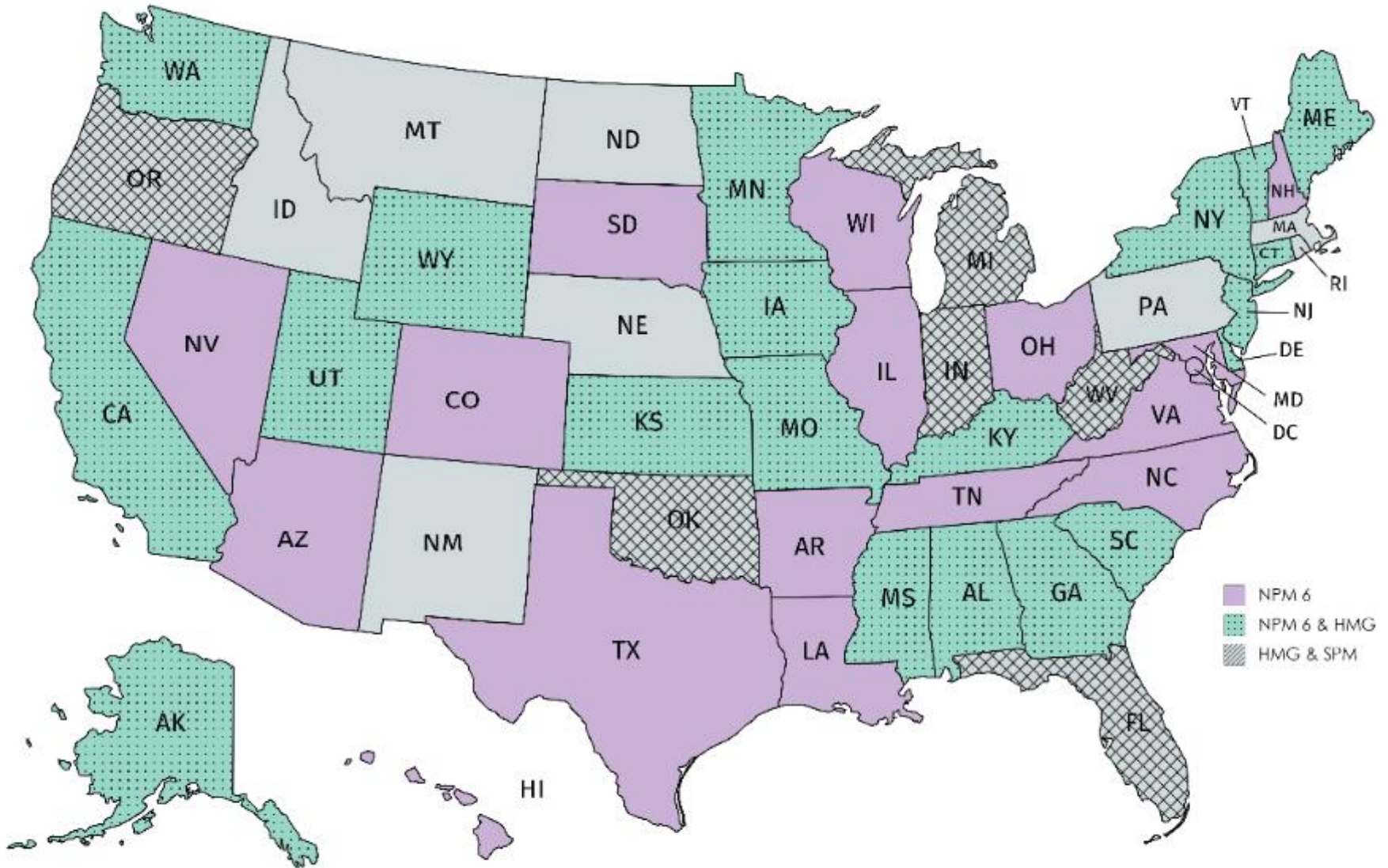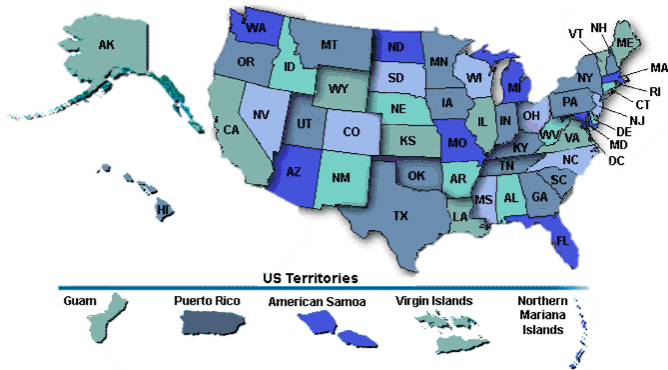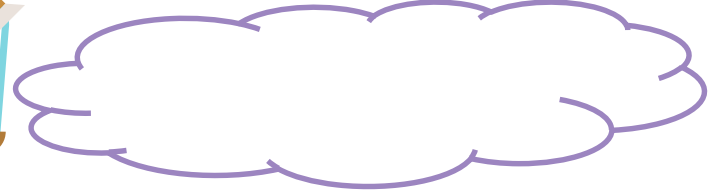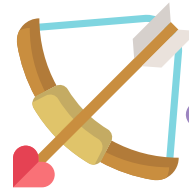
Title V MCH Programs

How does AMCHP provide support to states in addressing Developmental Screening?

How does AMCHP provide support to states in addressing Developmental Screening?

1. Training

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Training

Resources

eLearning

Publications

eLearning Module: Communicating the Value of Developmental Screening

- Identify the purpose of developmental screening
- Understand the impact screening has on families and children
- Recognize the roadblocks and challenges of the screening process
- Ascertain the role of Title V in developmental screening and communicate its value
- Identify additional resources to assist in communicating value

Communicating the Value of Developmental Screening

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http://bit.ly/2tgAz3A

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How does AMCHP provide support to states in addressing NPM 6?

1. Training

2. Systems Coordination

Systems Coordination

Learn the Signs. Act Early.

National Standards for Systems of Care for Children & Youth with Special Health Care Needs

Early Childhood Comprehensive Systems Collaborative Improvement & Innovation Network

HRSA State Planning and Implementation Grants for Improving Services for Children and Youth with ASD/DD
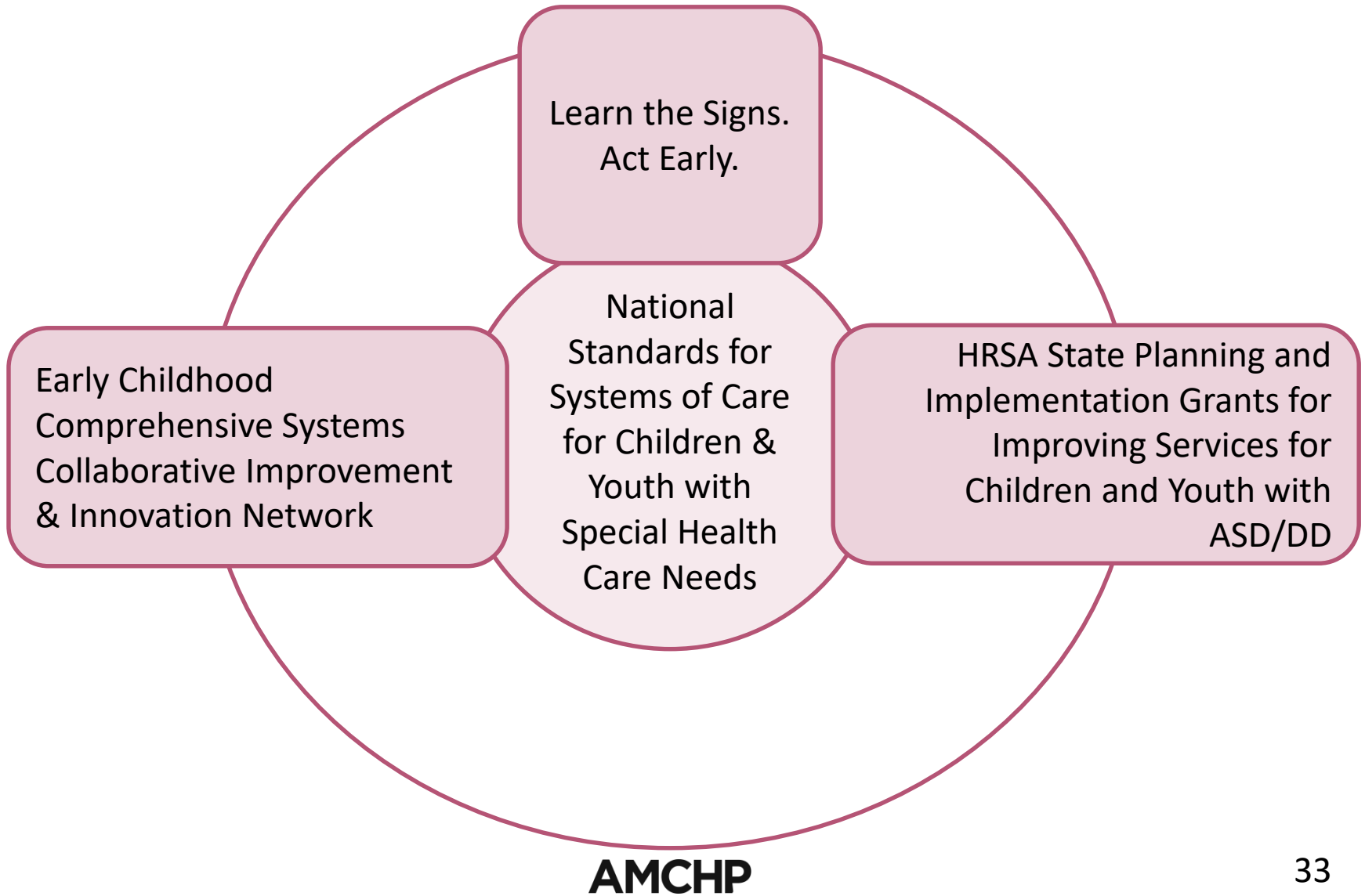
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LTSAE. AMCHP's State Systems Grant: Seven Years in Review

COMING SOON!

Learn the Signs. Act Early. (LTSAE)

State Systems Grant Outcomes

2011-2019

34 Thirty-four grantees improved their state's capacity for coordination of early education, identification, and intervention services for children with autism and other developmental disabilities. Below are the reported successes of the cohort as a whole.

Formalized Developmental Screening as a Priority

Enacted changes to policies or practices to conduct developmental monitoring and screening

- Integration of LTSAE materials into multiple systems
- Enhanced coordination of early identification and early intervention services

Activated Stakeholders and Strengthened Partnerships

Improved partnerships to strengthen state developmental screening systems

- Improved cross-state sharing and/or collaboration through the national Act Early network

Increased Awareness among Caregivers and Providers

Increased knowledge and training amongst early childhood providers

- Enhanced parent engagement in developmental monitoring

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A full issue brief on outcomes, including several detailed case studies, will be available by Summer 2019. When it's published, you can check it out here: https://bit.ly/2MVzSI3

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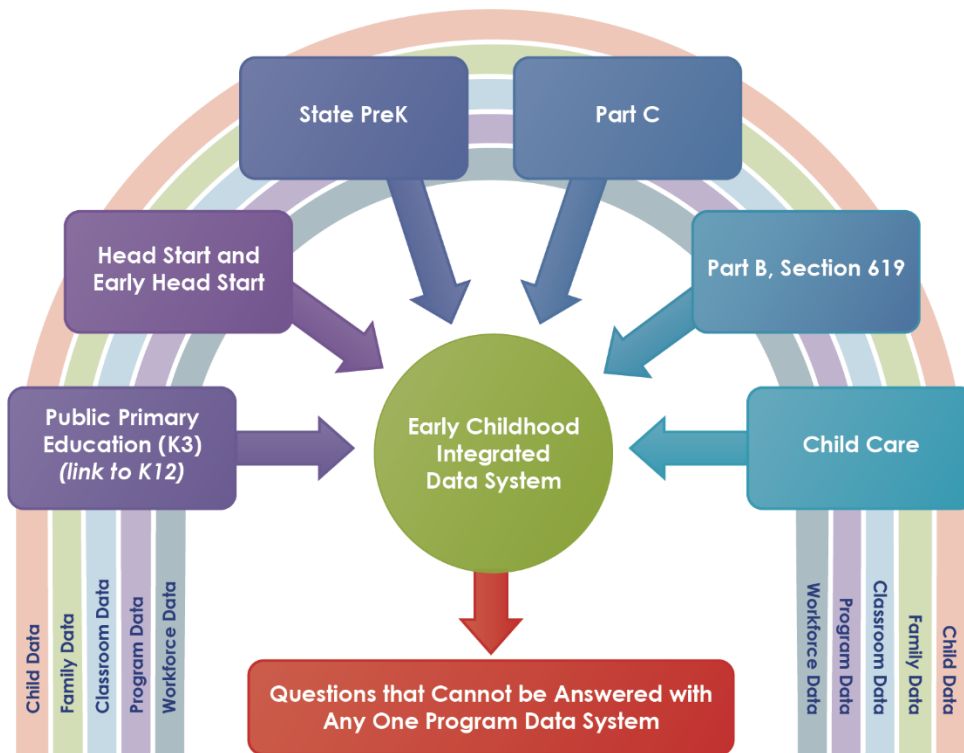# How does AMCHP provide support to states in addressing Developmental Screening?

1. Training

2. Systems Coordination
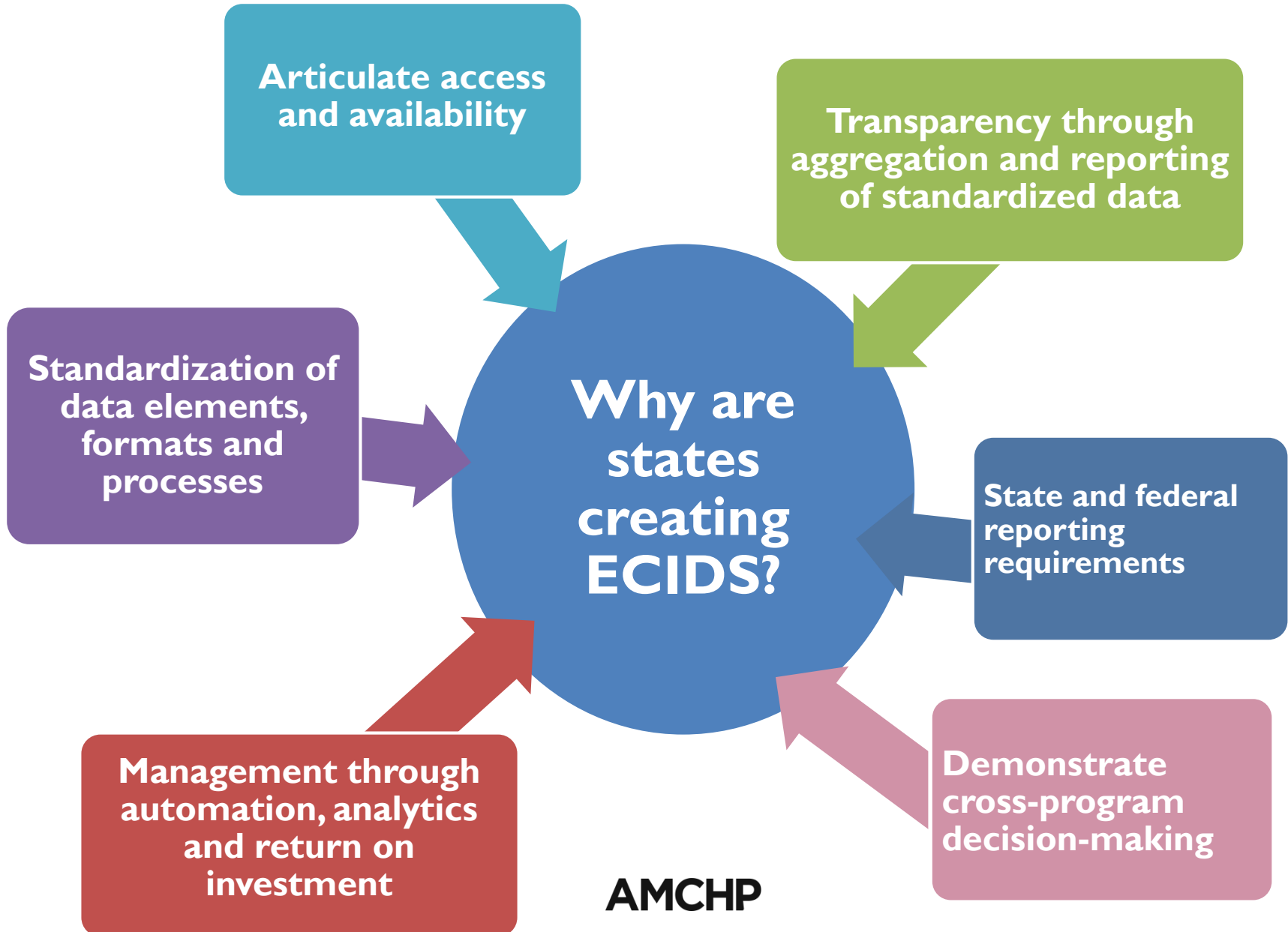
3. Data Integration

What is an ECIDS?

- Collects, integrates, maintains, stores, and reports information from early childhood programs
- Crosses **multiple agencies** within a state that serve children and families from birth to age 8
- Includes data on the individual child, the child's family, the classroom, the program/providers, and other services that provide comprehensive care and education for young children

•*(What is an ECIDS, NCES 2014)*

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Why are states creating ECIDS?

Articulate access and availability

Transparency through aggregation and reporting of standardized data

Standardization of data elements, formats and processes

Why are states creating ECIDS?

State and federal reporting requirements

Management through automation, analytics and return on investment

Demonstrate cross-program decision-making

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Status of linking child-level data across ECE programs

State links data between all or some ECE programs

State is planning to link data

State does not link data

Click on a state to view a profile of its detailed performance.
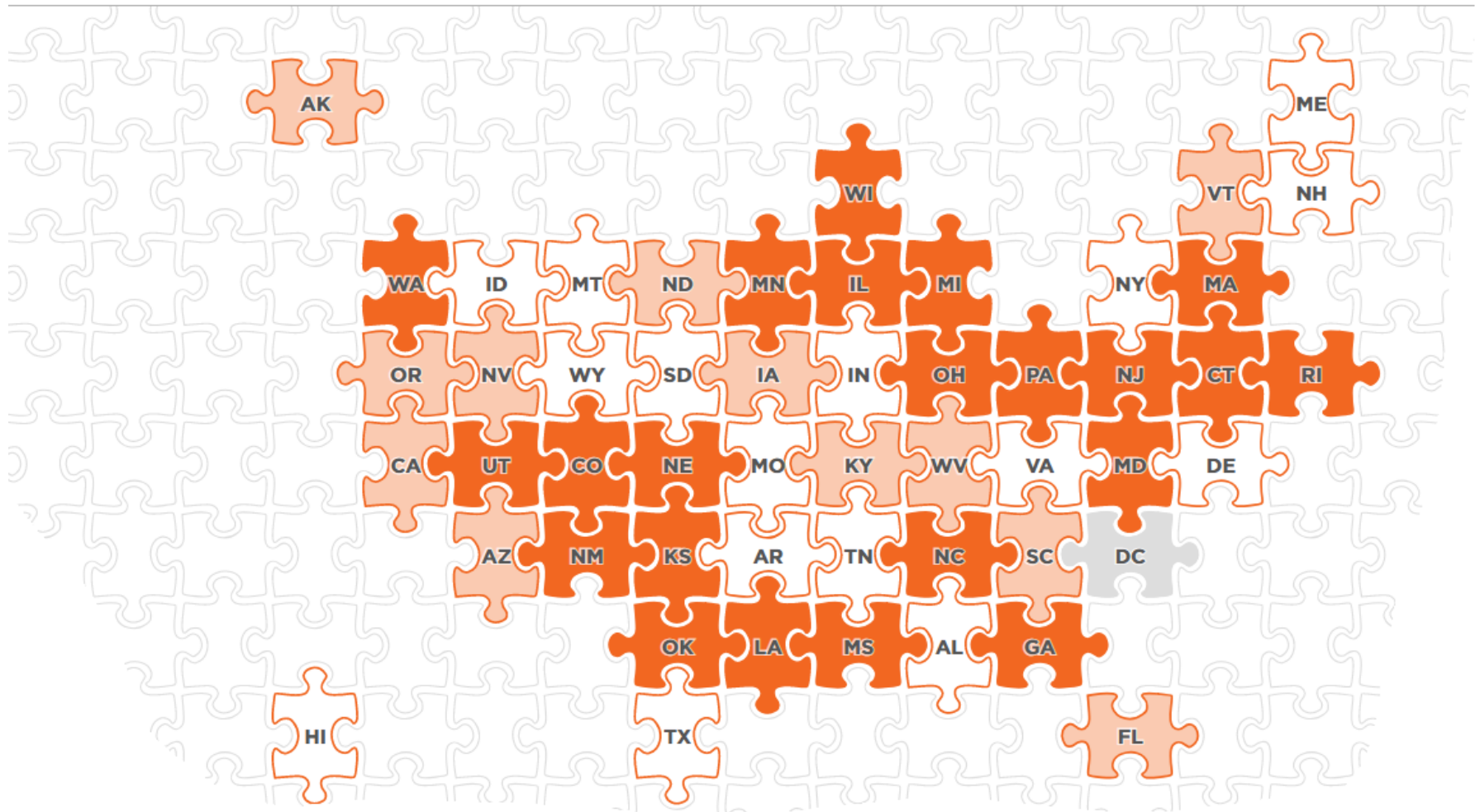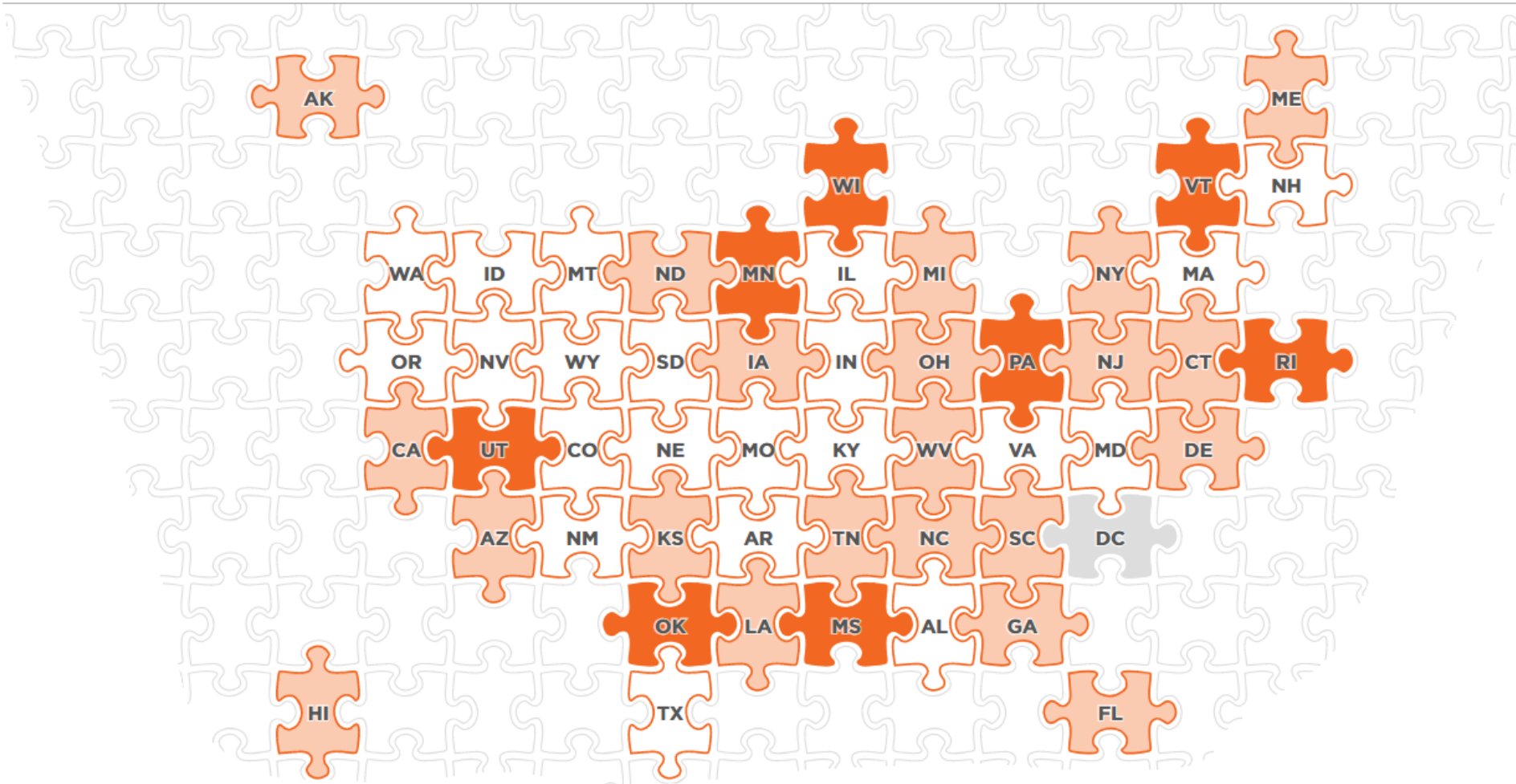
Status of linking child-level data with health data

State links some or all ECE programs w/health data

State is planning to link ECE programs w/ health data

State does not link ECE programs w/ health data

Click on a state to view a profile of its detailed performance.
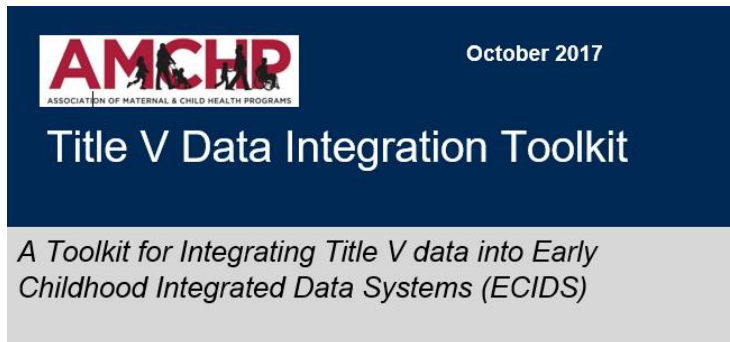
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Examples of Current Health Data Integration

- ECCS CoIIN and Impact Grantees
- MIECHV
- WIC
- Medicaid
- Intergenerational Poverty
- Vital Records
- Developmental Screening

- And Now.....

Title V!

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Data Integration

October 2017

Title V Data Integration Toolkit

A Toolkit for Integrating Title V data into Early Childhood Integrated Data Systems (ECIDS)

- Overview of ECIDS
- Value of integrating and sharing Title V data
- Tip sheets
- Use cases
- State examples

The Tip Sheets

- Purpose and Vision
- Data Privacy and Security
- Obtaining Leadership Support
- Getting a Seat at the Table
- Return on Investment
- Parental Consent

TITLE V DATA INTEGRATION TIP SHEET: OBTAINING LEADERSHIP SUPPORT

The successful integration of Title V data into an Early Childhood Integrated Data System (ECIDS) requires leadership support buy-in, which involves an element of co-creation. Through discussion, debate, idea generation, and identification of challenges and successes, Title V programs will understand the benefits of participating in ECIDS efforts, allowing everyone to feel more vested in data integration efforts.

✓ Listen to what Title V leaders and programs need to participate in ECIDS efforts and what they want back from the integrated data system. Ask question: What barriers may prevent participation? What would make data integration more relevant, attractive, or possible? What help do you need to prepare for data integration?

✓ Make your case for data integration. Share with leadership the benefits of participating in an ECIDS, including the ability to answer questions with data that one system alone cannot provide. Provide use cases showing how integrated data will help Title V programs meet their goals.

✓ Share ECIDS examples showing how data integration can reduce burden through publicly available data reports or dashboards meeting the needs of Title V data reporting at the state or federal level.

✓ Engage Title V leadership early and throughout the integration process to increase buy-in. Leadership should help develop the purpose and vision for integrating data, the policy questions needing to be answered with the ECIDS integrated data, data privacy, and safeguards, and provide input on the conditions under which their data may be shared with analysts or researchers.

✓ Ensure Title V leadership can communicate the vision, mission, purpose, and benefits of the ECIDS data integration.

✓ Provide regular reports to Title V leaders on ECIDS integration efforts and widely disseminate reports resulting from the ECIDS. Keeping Title V leadership informed about benefits, successes, and challenges ensures continued leadership buy-in.

Obtaining Leadership Support Resources and Tools
- Early Childhood Integrated Data Systems: Stakeholder Engagement
- The DaSy Center's Early Childhood Data System Framework: Stakeholder Engagement
- Communications Plan Template
- How to Get Real Buy-In for Your Idea
- Three Strategies for Instilling Leadership Buy-in

Title V Data Integration Toolkit   *Association of Maternal & Child Health Programs*

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The Use Cases

- Essential Title V questions needing integrated data to answer

- Suggested data elements that align to CEDS

- Example analysis and data visualization

- Possible actions based on data

- Topics
  - Developmental Screening
  - Autism
  - Community-Based Services

Title V Data Integration Use Case: Developmental Screening

In June 2015, AMCHP released Resources for Title V Action Planning: Developmental Screening Strategies and Measures. This document articulates the importance of screening for healthy development to help identify potential delay areas for further evaluation and diagnosis and for reducing the likelihood of developing other delays.[1]

As Title V programs strive to improve developmental screening and early identification, it becomes critical to have data to inform program decisions and strategically plan. This use case focuses on leveraging state ECIDS to provide insight into the state developmental screening landscape, including rates and results. The analysis can be customized for each Title V program allowing for an in-depth look into developmental screening data at the state or local level.

Use Case Questions

1. How many children birth through age 5 are receiving a developmental screening using a parent-completed screening tool?
2. How many children birth through age 5 are achieving five-domain developmental health as demonstrated by a parent-completed developmental screening results?

Analytic Considerations

The focus of this question is developmental screening outcomes. Therefore, all children included in the analysis will need to have received a developmental screening. As there may be many sources of developmental screening, decisions will need to be made on which parent-completed developmental screening Title V programs wish to review. For example, Title V programs may wish to analyze all screeners used within the state or may wish to look at outcomes by specific screeners such as the Ages and Stages Questionnaire, the Denver Developmental Screening Test, or the Battelle Developmental Inventory. If the Title V program wishes to have data on specific screeners (rather than all screeners), a list of these screeners must be provided to the ECIDS point of contact.

To work with developmental screener data, Title V programs must know which sources participating in the Early Childhood Integrated Data System (ECIDS) share data on developmental screening. Title V programs should also consider that children may have received multiple screenings from multiple sources. Title V programs will only be able to capture a unique count of children receiving developmental screening if the ECIDS assigns a unique identifier.

Title V programs will need to determine how they will use the data to determine how to pull the data. For example, is the Title V program interested in data from the total number of screenings done in a specified time or the total number of children receiving at least one screening in a specified time? Or perhaps only data from the most recent screening are needed. Once Title V

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[1] Resources for Title V Action Planning: Developmental Screening Strategies and Measures (June 2015)

Title V Data Integration Toolkit

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State Examples

- States share successes and challenges to integrating Title V data

- Includes state-specific data visualizations

- Includes advice for data integration

- States
  - Kentucky
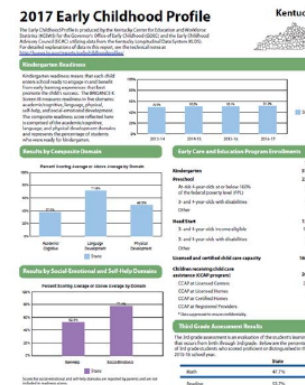 - North Carolina
  - Rhode Island

Title V Data Integration Toolkit

http://bit.ly/ToolkitFactSheet

Contact the State Support Team

- SST is an initiative of the SLDS Grant Program
- SST has experienced state data systems experts
- SST support is free and available to all states and territories
- SST assists via individual and multi-state assistance
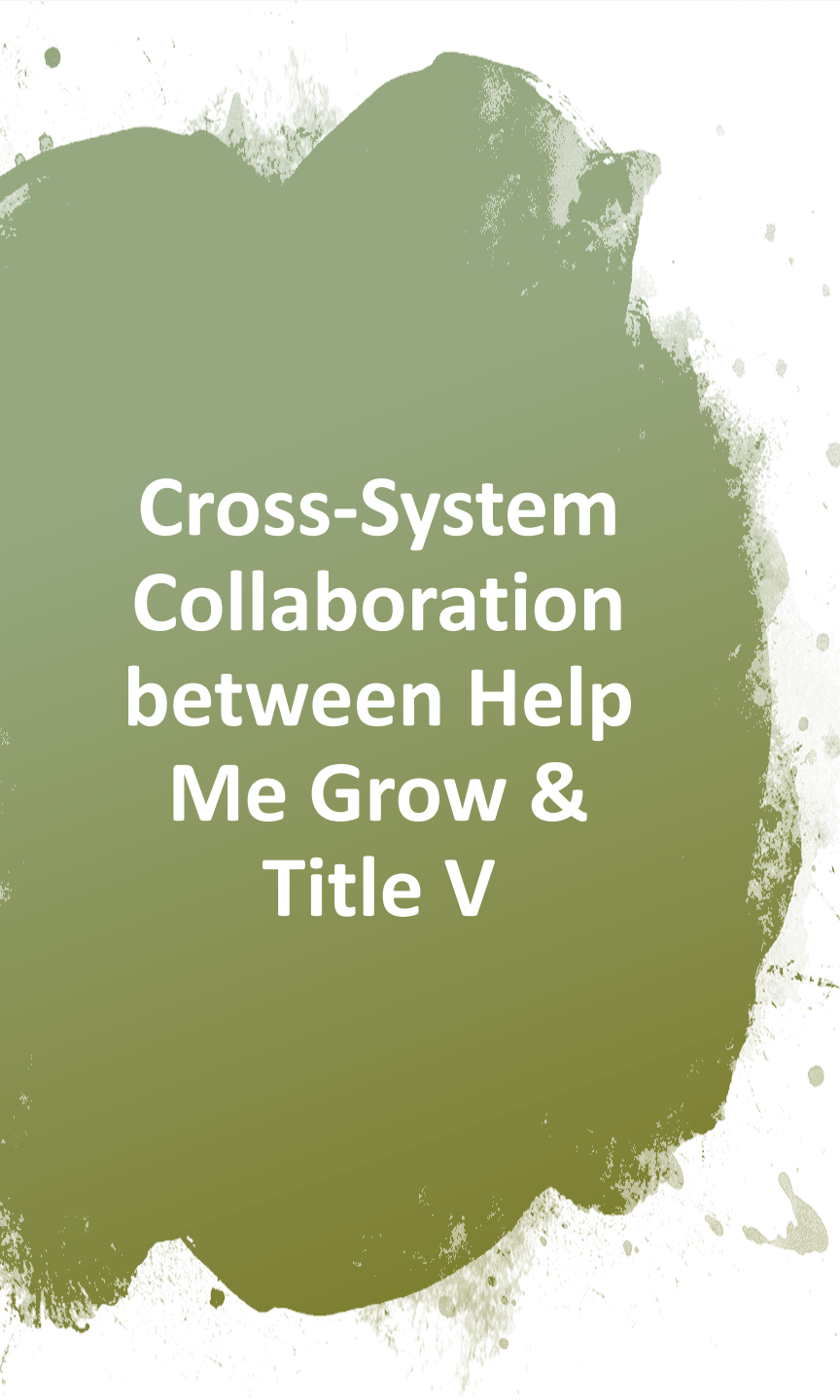
To Request SST Support:
Web: https://nces.grads360.org/#program/about-the-sst
Email: Support@sst-slds.org

Privacy Technical Assistance Center (PTAC)

- PTAC offers technical assistance related to the Privacy, Security, and Confidentiality including:
    - Site visits
    - Regional meetings
    - Privacy and security practice presentations
    - Privacy toolkit containing best practice guides and related resources
    - Data security policies, procedures, and architectures reviews
    - Data security audit assistance
    - Frequently asked questions (FAQs) and answers commonly requested by PTAC stakeholders
    - Help desk support on data privacy and security questions
- https://studentprivacy.ed.gov/

Privacy Technical Assistance Center
U.S. Department of Education

Cross-System Collaboration between Help Me Grow & Title V

- Develop and expand a shared resource for families and primary care providers of CYSHCN using the Help Me Grow centralized system model (AK)

- Expanding screening networks via HMG (MN, WA)

- Utah 211 and HMG have partnered with the CSHCN Bureau to provide referral and follow up services to families whose children do not qualify for early intervention, and have not been determined to have special health care needs.

Alabama

ESM: Establish an agreement with the Alabama Partnership for Children's Help Me Grow (HMG) Program to utilize their online ASQ-3 assessment tool so that parents can complete developmental screens **PRIOR** to child health visits at county health departments.

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Vermont

- Implement early surveillance and screening for all children and link them to existing quality programs and services through HMG system in Vermont

- Promote and expand *Help Me Grow* Vermont to promote optimal child development by enhancing protective factors

- Title V worked with the HMG Leadership and Sustainability Team to begin implementation of the four Core Components of HMG

- Data collection for HMG staff to monitor work and identify areas for improvement: community outreach, family outreach, and marketing.

What questions, insights, or comments do you have?

Let's do an activity!

What's a Data Story?

- Brief structured analysis that provides data visuals with insightful narrative in a sharable format.

- Allows audience to quickly understand the insight the data offers and the message the creator is communicating

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What's the Purpose of a Data Story?

DEMONSTRATE A SUCCESS

DEMONSTRATE A PROGRAM/SERVICE NEED
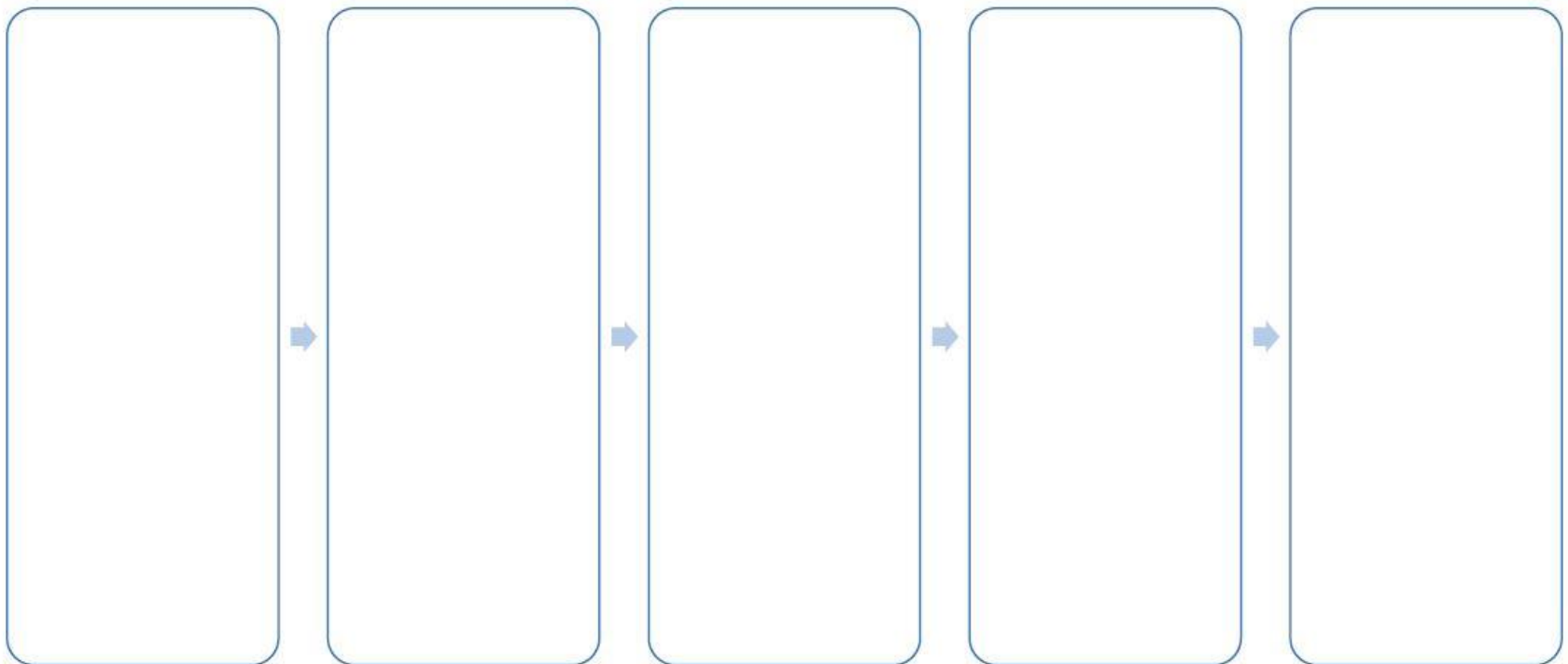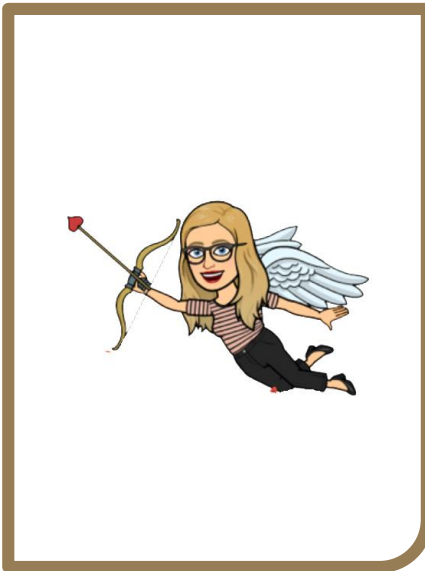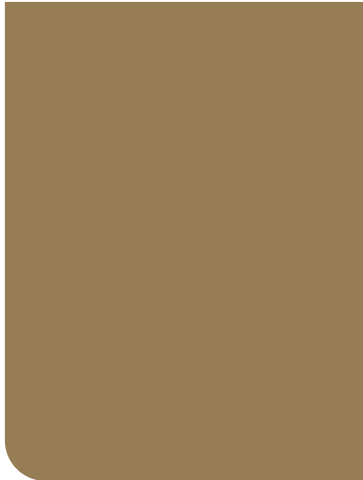
DEMONSTRATE AN INFORMATION NEED

STATE A GOAL/PRIORITY

EXAMINE A TREND

MEASURE PROGRESS TOWARD A PERFORMANCE TARGET

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ECDataWorks
Advancing Early Childhood Policy and Programs
through Strategic Use of Integrated Data

Data Story Template

Identify the Question	→	Collect Data	→	Answer Question	→	Develop Data Story	→	Share Your Message

What's Next?

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Advance your great work by connecting with Title V staff in your state or territory!

REMEMBER: AMCHP can be your "cupid" to support your connection

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We'd love to hear your feedback!

Please visit the following link to provide feedback with us via SurveyMonkey:

https://www.surveymonkey.com/r/JKRDPZ9

OR

http://bit.ly/amchpHMG

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SPHARC
State Public Health Autism Resource Center

www.amchp.org/SPHARC

Paige Bussanich
Senior Program Manager,
Child and Adolescent Health
pbussanich@amchp.org