

Partnering with Title V Programs to Integrate Child Welfare Data into Early Childhood Integrated Data Systems (ECIDS)



National Child Welfare Evaluation Summit | Washington, DC
August 20, 2019 10:45AM-12:15PM EST | Room: Hoover

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
- ✓ Systems of Care
- ✓ Developmental Monitoring & Screening
- ✓ Zika response

Co-Presenter

Kate Taft, MPH

ktaft@amchp.org

Ask me about:

- ✓ Child and Adolescent Health
- ✓ Maternal and Child Environmental Health/Lead Poisoning Prevention
- ✓ Early Child Development
- ✓ Systems of Care
- ✓ Zika and emerging issues
- ✓ Screening systems

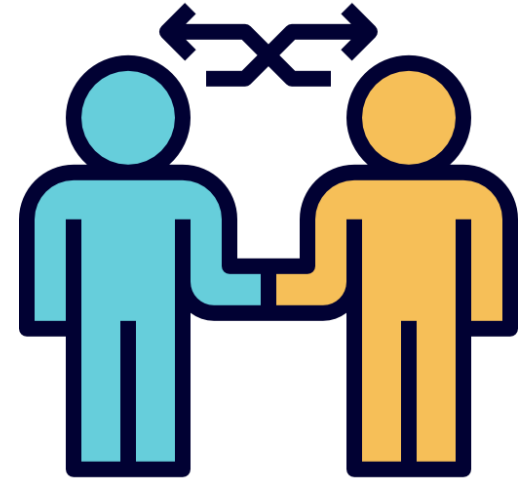


Associate Director

Child & Adolescent Health

Who's in the room?

- Name
- State
- Title
- Organization
- Are you familiar with Title V of the Social Security Act?
- If you could use only ONE type of data for the rest of your career, would you choose **QUANTITATIVE** or **QUALITATIVE**?



Agenda

- Who is AMCHP? What is Title V?
....and why this matters for child welfare
- Introduction of AMCHP Data Integration toolkit
- Q & A/Discussion
- Activity: Creating your Data Story
- Examples
- Opportunities for partnership
- Session Evaluations



Learning Objectives

1. Identify opportunities for cross-system collaboration between Title V & child welfare organizations to support data integration.
2. Understand the role of data integration within a comprehensive system of services necessary for optimal outcomes for children, youth, and their families.

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.



How does AMCHP provide support to states in implementing systems of care for children and youth with special health care needs?

SPHARC 

State Public Health Autism Resource Center

www.amchp.org/SPHARC



OUR AIM



is to help increase state capacity to implement systems of care for children and youth with ASD/DD.

AMCHP

How does AMCHP provide support to states in implementing systems of care?



1. Training

Training



Resources

eLearning



AMCHP



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 importance of developmental screening and communicate its value
- **Identify** additional resources to assist in communicating value



<http://bit.ly/2tgAz3A>

How does AMCHP provide support to states in implementing systems of care?

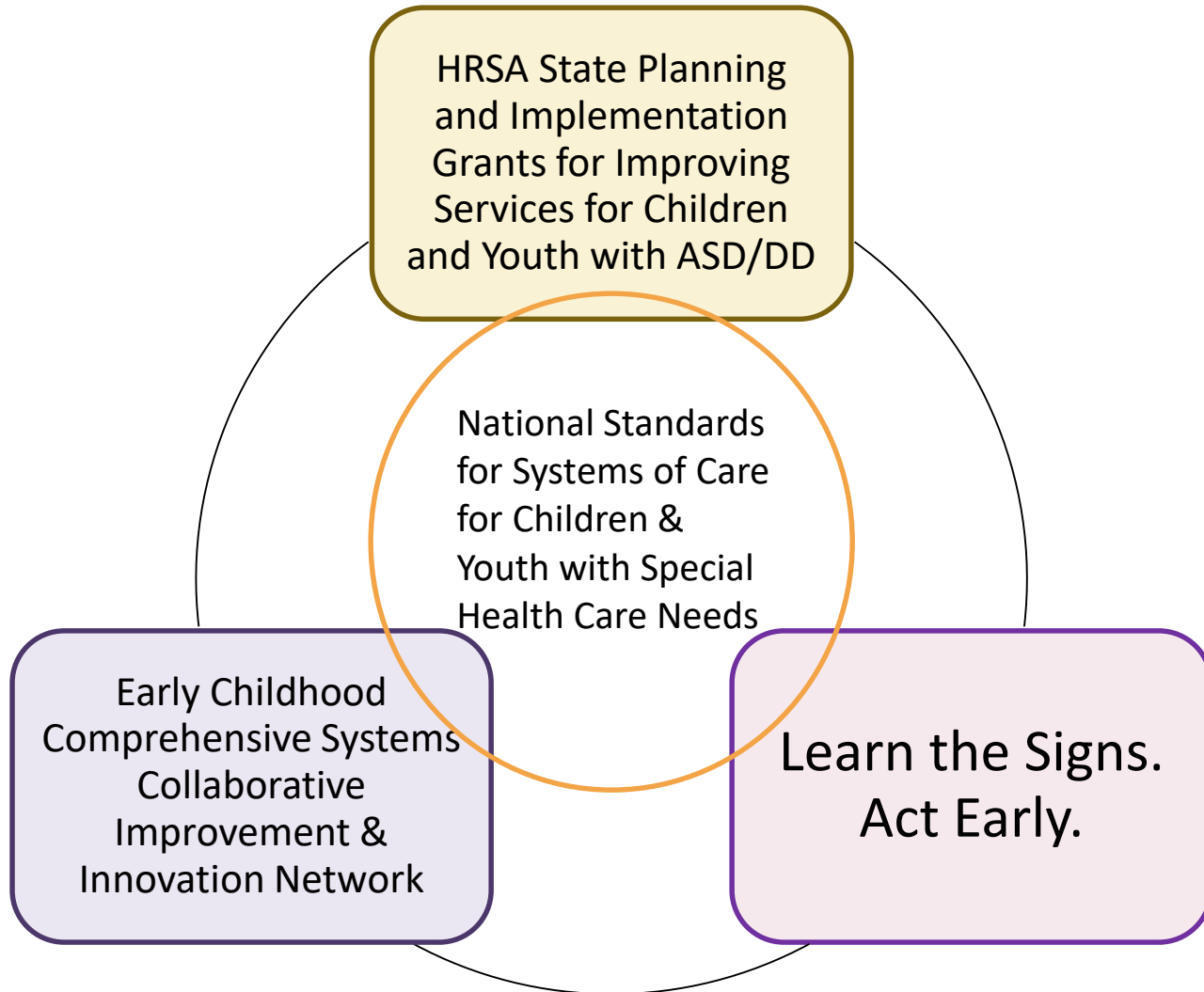


1. Training

**2. Systems
Coordination**



Systems Coordination



How does AMCHP provide support to states in implementing systems of care?



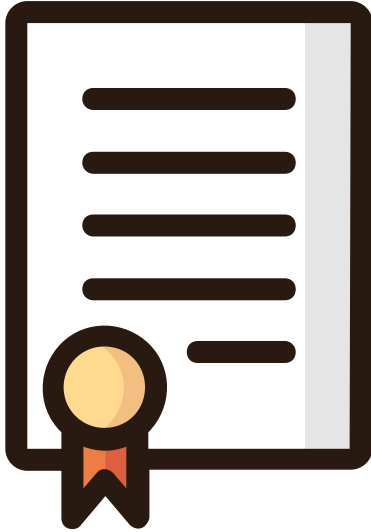
1. Training

**2. Systems
Coordination**



**3. Data
Integration**

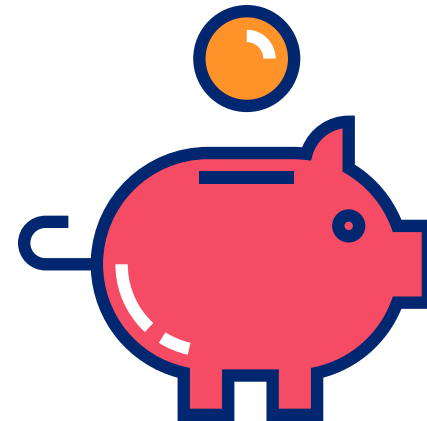
What is Title V?



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



Title V MCH Services Block Grants



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

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



Next
stop:
2020!

Title V Performance Measurement Framework

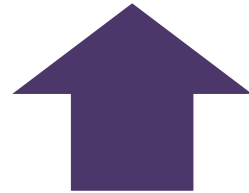
National Outcome Measures

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

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

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

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 are required to select 5 National Performance Measures (out of 15) and can also develop State Performance Measures to address other identified priority needs



Example: Alaska

National Outcome Measures 15 & 16.1

Child and Adolescent Mortality



State Performance Measure

Percent of deaths among children ages 0-17 years classified as maltreatment-related by the Maternal & Child Death Review committee



Evidence-Based/Informed Strategy Measure

Improve public access to child welfare data by making count and rate data available through the Indicator-Based Information System for Public Health. This system will allow users to extract information they need to support efforts, make decisions, and reduce the burden data requests made to child welfare and public health.

Title V Alignment with Child Welfare Systems

- 2012 Memorandum from the Administration on Children, Youth and Families (ACYF-CB-IM-12-04)
 - Promote social and emotional well-being for children and youth receiving child welfare services, and to encourage child welfare agencies to focus on improving the behavioral and social-emotional outcomes for children who have experienced abuse and/or neglect.

Appendix 1: ACYF Well-Being Framework

| | Intermediate Outcome Domains | | Well-Being Outcome Domains | | | |
|--|---|---|--|--|---|---|
| | Environmental Supports | Personal Characteristics | Cognitive Functioning | Physical Health and Development | Emotional/Behavioral Functioning | Social Functioning |
| Infancy (0-2) | Family income, family social capital, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) | Temperament, cognitive ability | Language development | Normative standards for growth and development, gross motor and fine motor skills, overall health, BMI | Self-control, emotional management and expression, internalizing and externalizing behaviors, trauma symptoms | Social competencies, attachment and caregiver relationships, adaptive behavior |
| Early Childhood (3-5) | Family income, family social capital, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) | Temperament, cognitive ability | Language development, pre-academic skills (e.g., numeracy), approaches to learning, problem-solving skills | Normative standards for growth and development, gross motor and fine motor skills, overall health, BMI | Self-control, self-esteem, emotional management and expression, internalizing and externalizing behaviors, trauma symptoms | Social competencies, attachment and caregiver relationships, adaptive behavior |
| Middle Childhood (6-12) | Family income, family social capital, social support, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) | Identity development, self-concept, self-esteem, self-efficacy, cognitive ability | Academic achievement, school engagement, school attachment, problem-solving skills, decision-making | Normative standards for growth and development, overall health, BMI, risk-avoidance behavior related to health | Emotional intelligence, self-efficacy, motivation, self-control, prosocial behavior, positive outlook, coping, internalizing and externalizing behaviors, trauma symptoms | Social connections and relationships, social skills, adaptive behavior |
| Adolescence (13-18) | Family income, family social capital, social support, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) | Identity development, self-concept, self-esteem, self-efficacy, cognitive ability | Academic achievement, school engagement, school attachment, problem solving skills, decision-making | Overall health, BMI, risk-avoidance behavior related to health | Emotional intelligence, self-efficacy, motivation, self-control, prosocial behavior, positive outlook, coping, internalizing and externalizing behaviors, trauma symptoms | Social competence, social connections and relationships, social skills, adaptive behavior |
| <i>Social and Emotional Well-Being Domains</i> | | | | | | |

Intermediate Outcome Domains

| Title V | |
|---|--|
| National Outcome Measures | National Performance Measures |
| <ul style="list-style-type: none"> • Drinking during pregnancy • Postpartum depression • Neonatal abstinence syndrome • Health insurance status • Unable to access health care | <ul style="list-style-type: none"> • Safe sleep |

| Title V | |
|---|--|
| National Outcome Measures | National Performance Measures |
| <ul style="list-style-type: none"> •Preterm/ Early Term birth •Newborn screening timely follow-up •Autism •ADD/ADHD | <ul style="list-style-type: none"> •Breastfeeding •Developmental screening |
| <ul style="list-style-type: none"> •Autism •ADD/ADHD •Mental health treatment | <ul style="list-style-type: none"> •Bullying •Adolescent well-visit •Transition |

| | Environmental Supports |
|-------------------------|---|
| Infancy (0-2) | Family income, family social capital, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) |
| Early Childhood (3-5) | Family income, family social capital, community factors (e.g., institutional resources, collective socialization, community organization, neighborhood SES) |
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| Personal Characteristics |
|---|
| Temperament, cognitive ability |
| Temperament, cognitive ability |
| Identity development, self-concept, self-esteem, self-efficacy, cognitive ability |
| Identity development, self-concept, self-esteem, self-efficacy, cognitive ability |

Well-Being Outcome Domains

| | | Title V | | Title V | | |
|-------------------------|--|---|---|--|--|--|
| | | National Outcome Measures | National Performance Measures | Physical Health and Development | National Outcome Measures | National Performance Measures |
| Infancy (0-2) | Cognitive Functioning | <ul style="list-style-type: none"> • Newborn screening • Autism • ADD/ADHD | <ul style="list-style-type: none"> • Developmental screening | Normative standards for growth and development, gross motor and fine motor skills, overall health, BMI | <ul style="list-style-type: none"> • Newborn screening • Autism • Low birth weight | <ul style="list-style-type: none"> • Developmental screening |
| | Language development | | | | | |
| | Language development, pre-academic skills (e.g., numeracy), approaches to learning, problem-solving skills | | | | | |
| | Academic achievement, school engagement, school attachment, problem-solving skills, decision-making | | | | | |
| Early Childhood (3-5) | Language development, pre-academic skills (e.g., numeracy), approaches to learning, problem-solving skills | <ul style="list-style-type: none"> • School readiness • Autism • ADD/ADHD | <ul style="list-style-type: none"> • Developmental screening | Normative standards for growth and development, gross motor and fine motor skills, overall health, BMI | <ul style="list-style-type: none"> • School readiness • Autism • Obesity | <ul style="list-style-type: none"> • Developmental screening • Physical activity |
| | Academic achievement, school engagement, school attachment, problem-solving skills, decision-making | | | | | |
| Middle Childhood (6-12) | Academic achievement, school engagement, school attachment, problem-solving skills, decision-making | <ul style="list-style-type: none"> • Autism • ADD/ADHD • Mental Health treatment | <ul style="list-style-type: none"> • Bullying • Adolescent well-visit | Normative standards for growth and development, overall health, BMI, risk-avoidance behavior related to health | <ul style="list-style-type: none"> • Autism • ADD/ADHD • Mental Health treatment • Obesity | <ul style="list-style-type: none"> • Physical activity • Adolescent well-visit |
| Adolescence (13-18) | Academic achievement, school engagement, school attachment, problem solving skills, decision-making | | | | | |
| | | | | Overall health, BMI, risk-avoidance behavior related to health | | |

Social & Emotional Well-Being Outcome Domains

| | | Title V | | Title V | | | | | | |
|--|---|--|--|---|---|--|--|---|---|--|
| | | National Outcome Measures | National Performance Measures | National Outcome Measures | National Performance Measures | | | | | |
| <table border="1"> <thead> <tr> <th>Emotional/Behavioral Functioning</th> </tr> </thead> <tbody> <tr> <td>Infancy (0-2)</td> </tr> <tr> <td>Early Childhood (3-5)</td> </tr> <tr> <td>Middle Childhood (6-12)</td> </tr> <tr> <td>Adolescence (13-18)</td> </tr> </tbody> </table> | Emotional/Behavioral Functioning | Infancy (0-2) | Early Childhood (3-5) | Middle Childhood (6-12) | Adolescence (13-18) | <p>Self-control, emotional management and expression, internalizing and externalizing behaviors, trauma symptoms</p> | <ul style="list-style-type: none"> • Autism | <ul style="list-style-type: none"> • Developmental screening | <p>Social Functioning</p> <p>Social competencies, attachment and caregiver relationships, adaptive behavior</p> | <ul style="list-style-type: none"> • Breastfed • Newborn screening • Autism • Neonatal abstinence syndrome |
| | Emotional/Behavioral Functioning | | | | | | | | | |
| | Infancy (0-2) | | | | | | | | | |
| | Early Childhood (3-5) | | | | | | | | | |
| Middle Childhood (6-12) | | | | | | | | | | |
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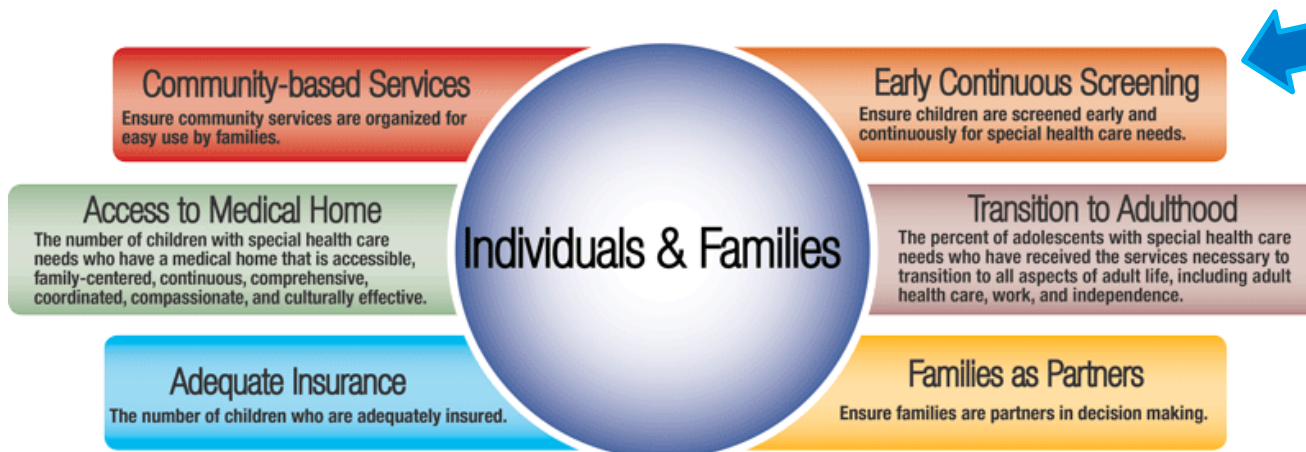
Screening is an important piece of early childhood services...



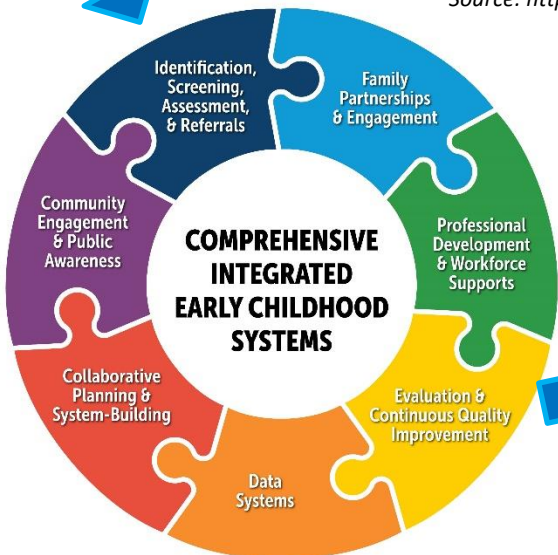
Linkage to appropriate, coordinated care and services
for the child and family

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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Bright Futures™
prevention and health promotion for infants, children, adolescents, and their families™

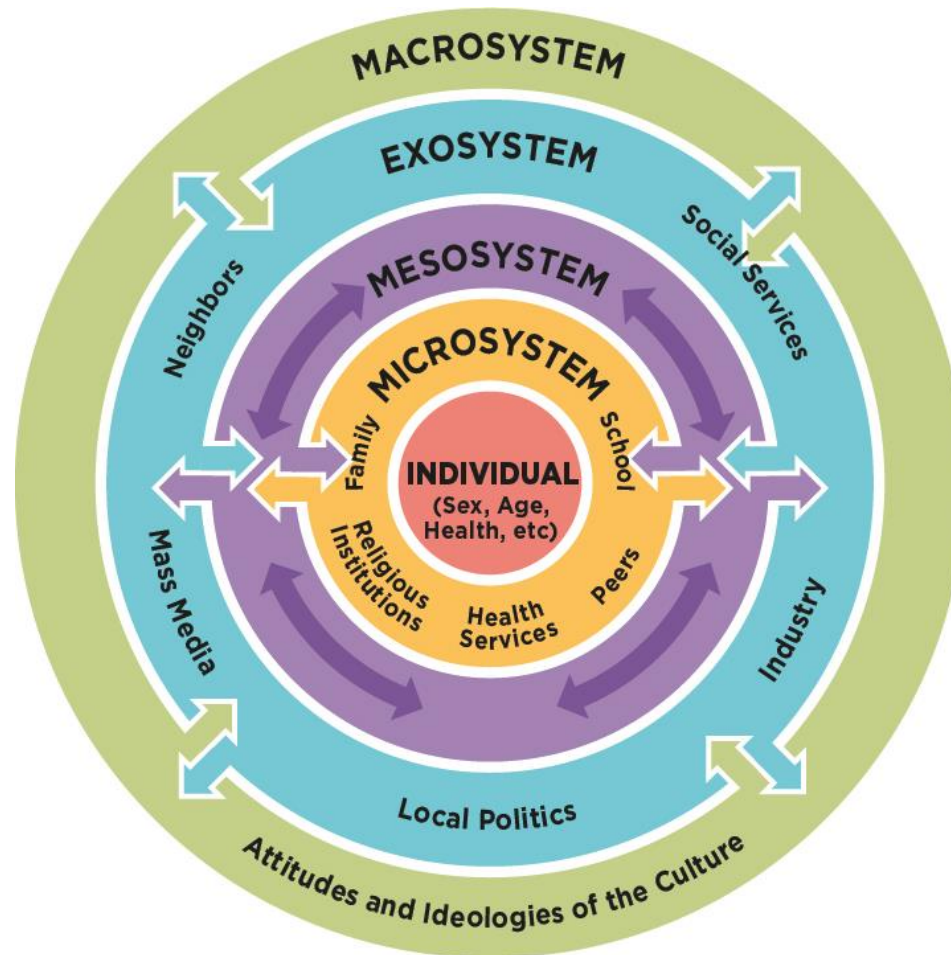
Recommendations for Preventive Pediatric Health Care
Health Future Research Academy of Pediatrics

National Standards for CYSHCN

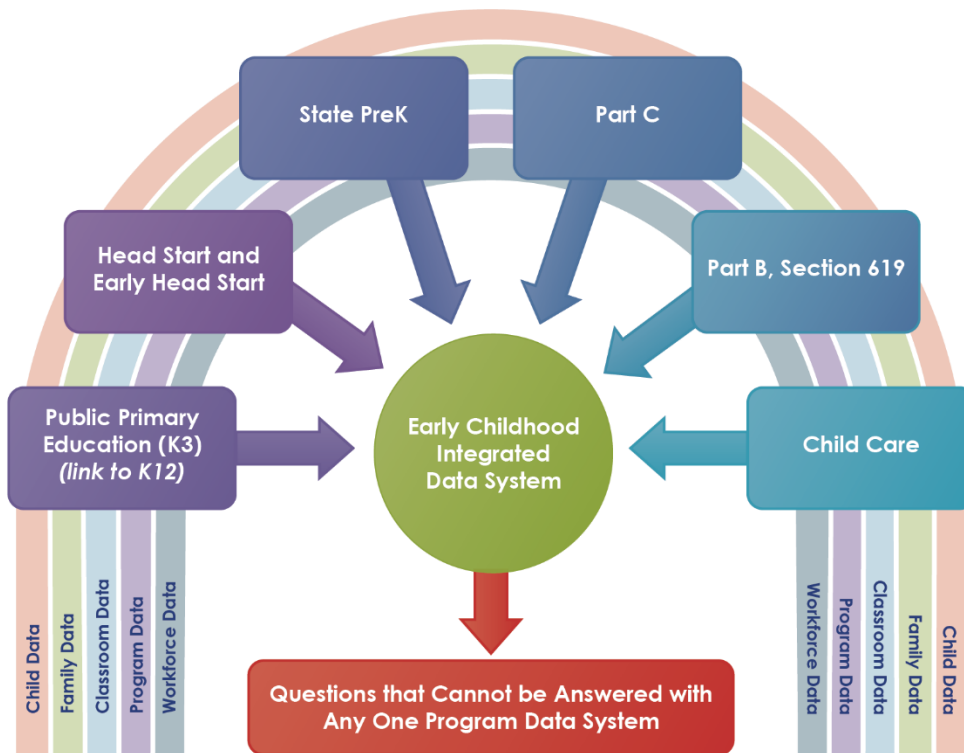
| | |
|---|---|
| 1 | Identification, Screening, Assessment, and Referral |
| 2 | Eligibility and Enrollment in Health Coverage |
| 3 | Access to Care |
| 4 | Medical Home |
| 5 | Community-Based Services and Supports |
| 6 | Transition to Adulthood |
| 7 | Health Information Technology |
| 8 | Quality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

*Early Childhood Integrated
Data Systems*
or
ECIDS

ECIDS applies the Ecological Systems theory to data systems



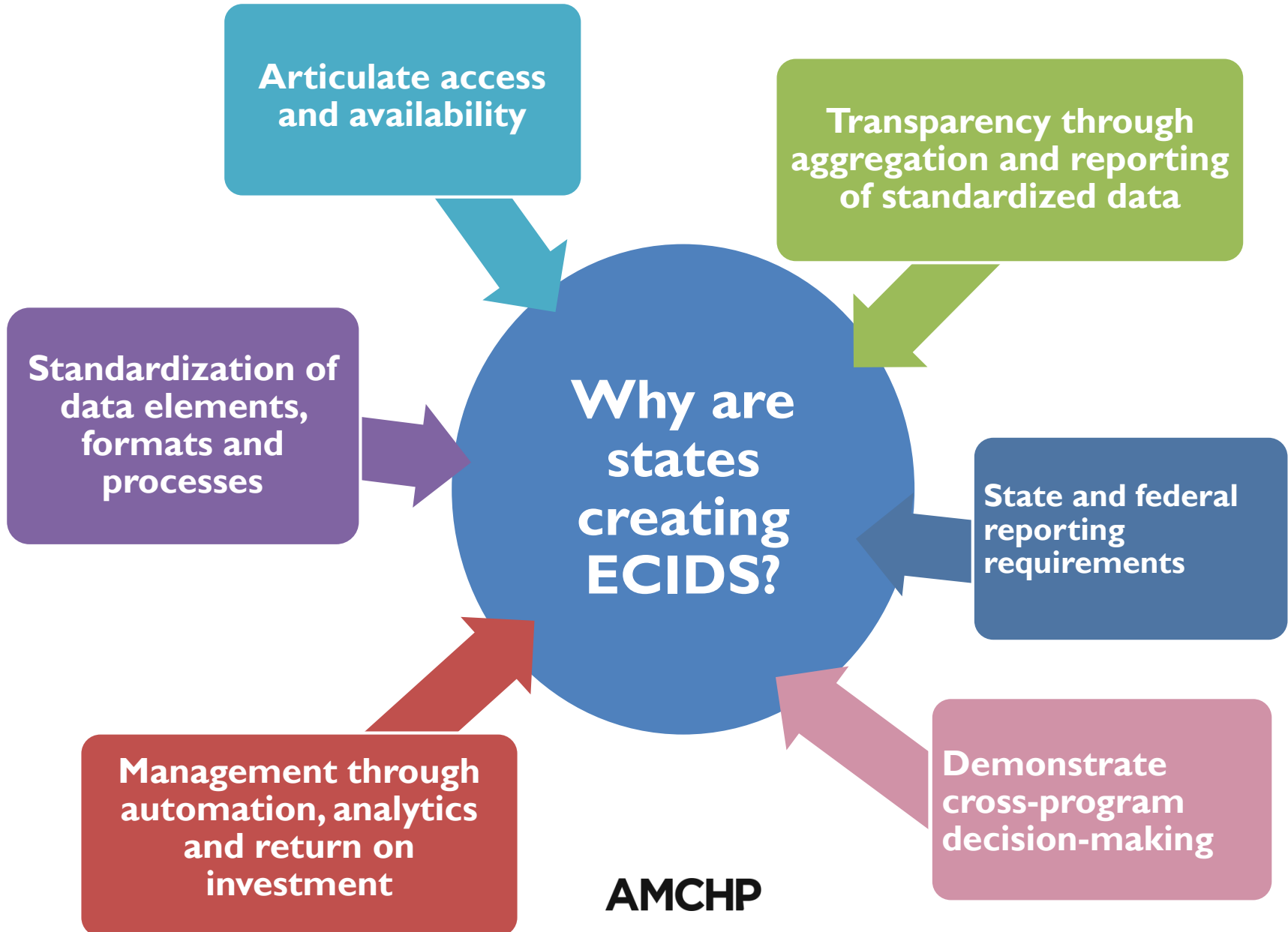
What is an ECIDS?






- 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)

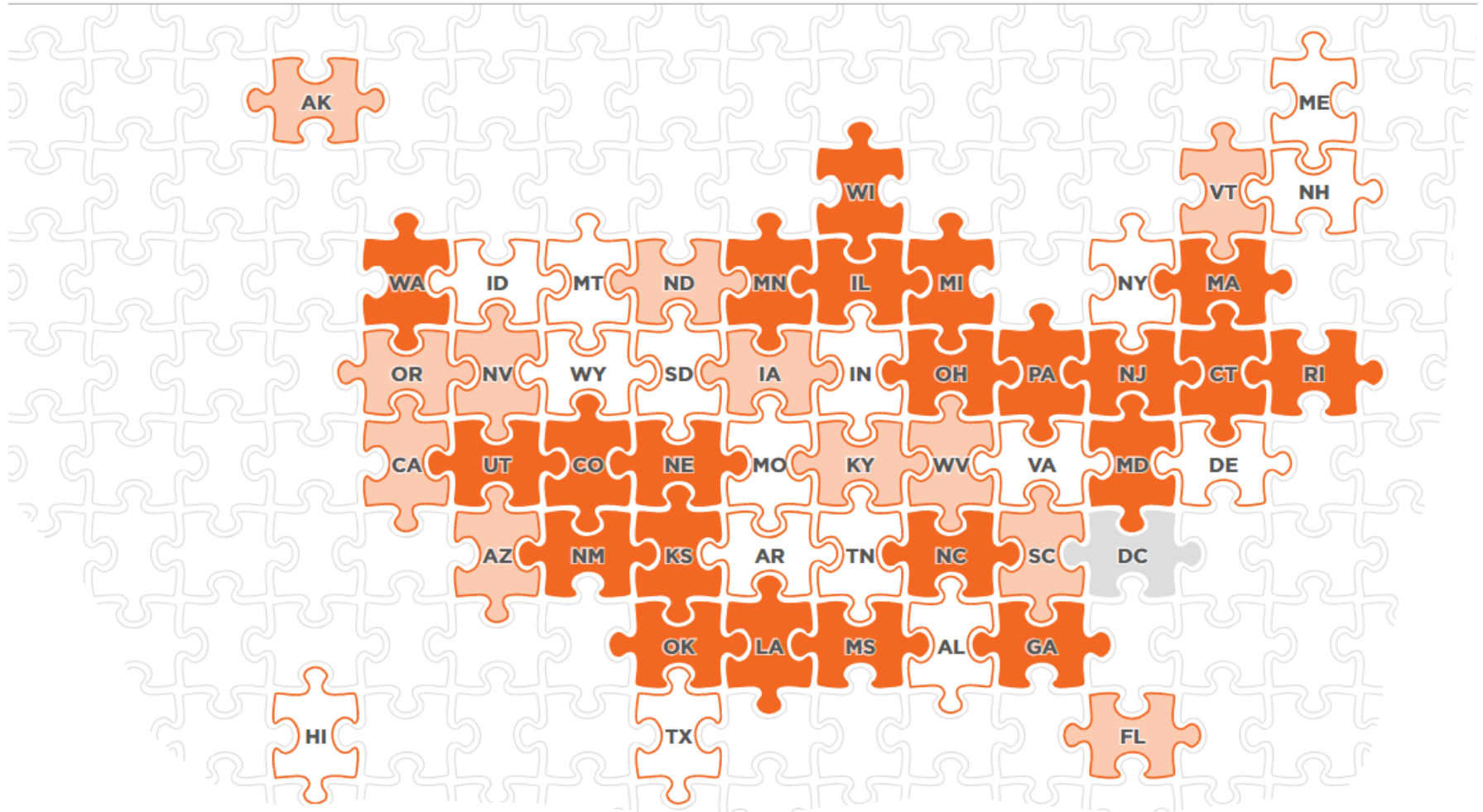
Why are states creating ECIDS?



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.




<https://www.ecedata.org/2018-state-of-early-childhood-data-systems/#map>

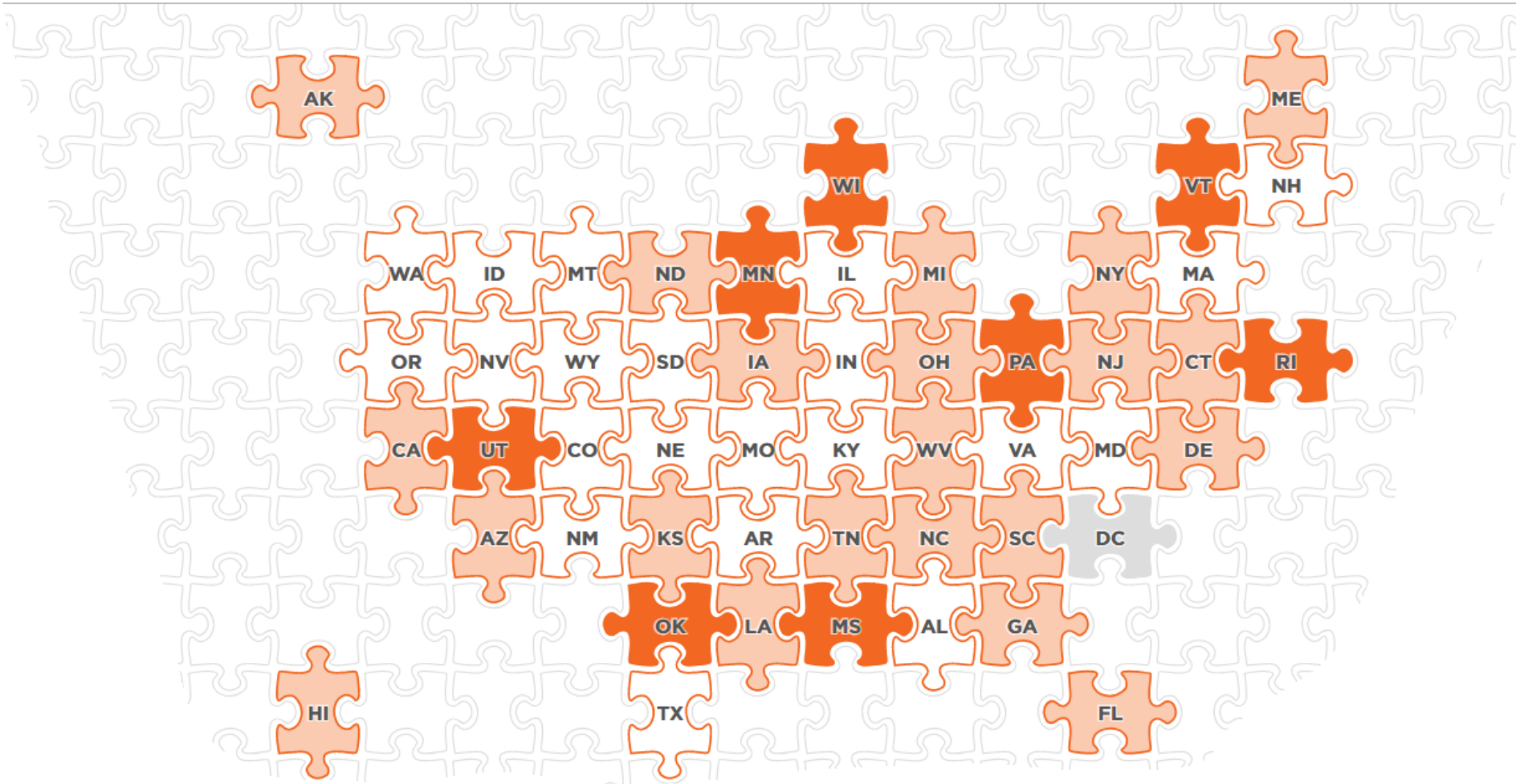
Status of linking child-level data with health data

 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.




<https://www.ecedata.org/2018-state-of-early-childhood-data-systems/#map>

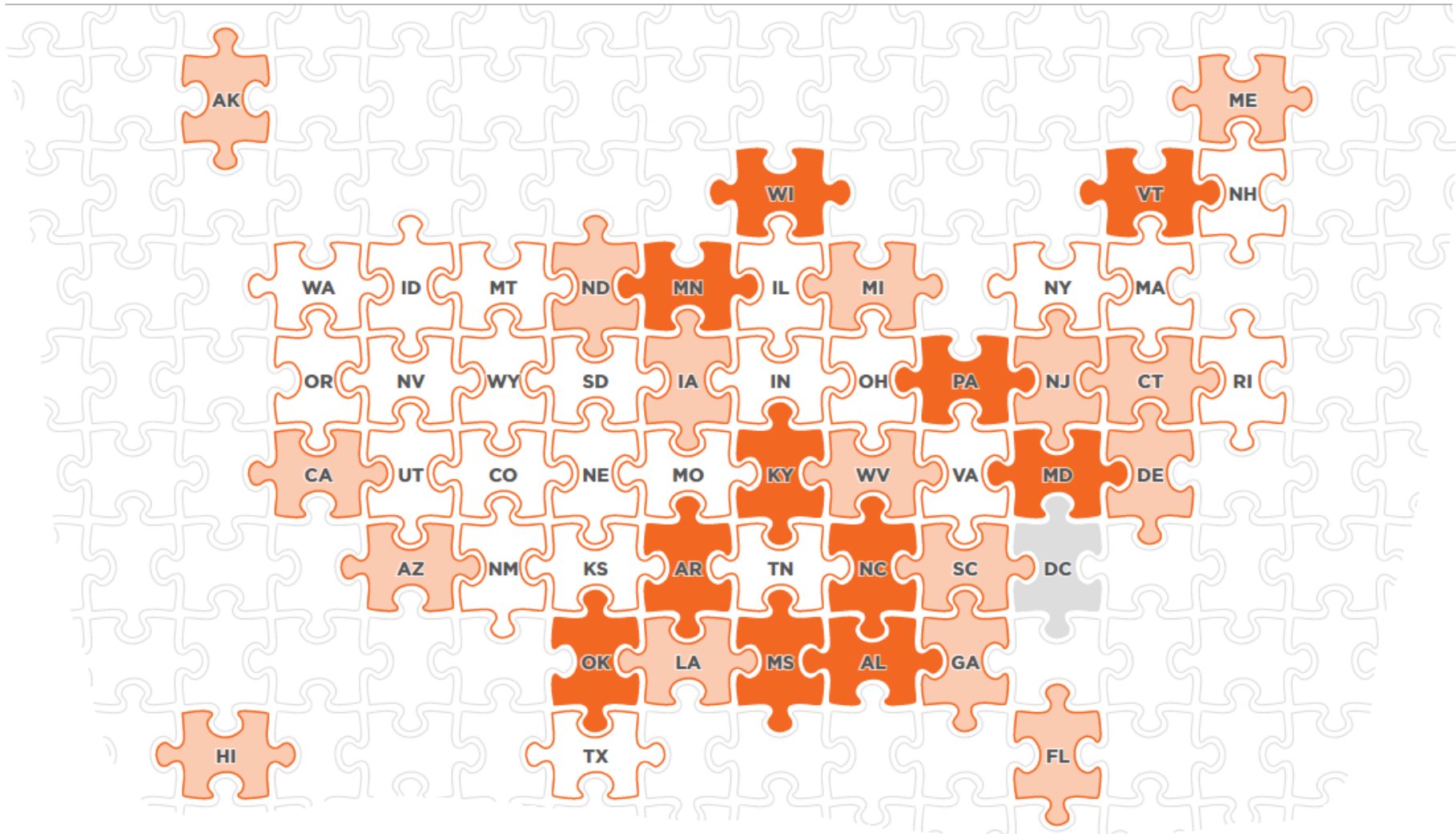
Status of linking child-level data with social services data

 State links all or some ECE programs w/social services data

 State is planning to link ECE programs w/ social services data

 State does not link ECE programs w/ social services data

Click on a state to view a profile of its detailed performance.



Let's look at an example...

Rhode Island: Early Care and Education and Child Welfare

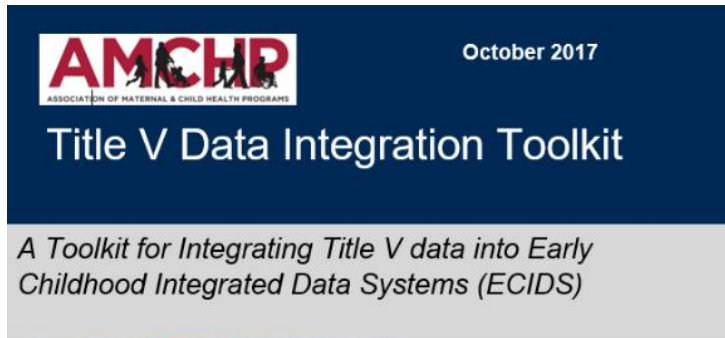
- Rhode Island KIDS COUNT conducted a demonstration project with the goal of integrating early care and education data across systems to examine the number of young children involved in the child welfare system participating in early care and education programs.

- Matched child level data across state agencies

https://www.ecedata.org/wp-content/uploads/2018/11/ECDC_KIDSCOUNT_ECIDS_Report..pdf



Title V Data Integration Toolkit



<http://bit.ly/TitleVtoolkit>



Developed Through Title V Input

Workgroup

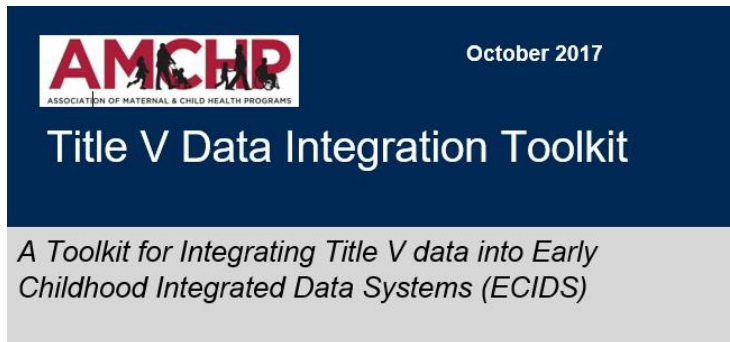
- 9, 1 ½ hour workgroup calls
April - July 2017

Provided insight and feedback on:

- Value of integrating and sharing Title V data
- Identification of Title V essential questions
- Identification of potential shared Title V data elements
- Use case examples



Data Integration



- 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](#)

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

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

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

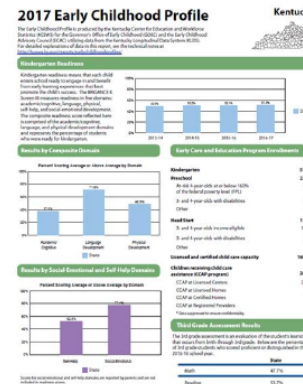
Title V Data Integration State Example: Kentucky

Background: State System

The Governor's Office of Early Childhood (GOEC) in Kentucky received funding through the Race to the Top – Early Learning Challenge in 2013. One of the objectives of the grant was to integrate data into Kentucky's Longitudinal Data System (K LDS). This system is maintained by the Kentucky Center for Education and Workforce Statistics (KCEWS). This system initially only included data on higher education, K-12, and teacher licensure. Data on workforce and non-education services were later added.



Integration & Use of Public Health Data



Once the state had successfully established its system for integrated data, KCEWS developed several reports and white papers primarily focused on postsecondary and workforce data. In 2015, KCEWS, in collaboration with GOEC and the Early Childhood Advisory Council, used data from the K LDS to develop a county-level "Early Childhood Profile". This profile includes a combination of data from the K LDS and data that are to be added to the K LDS in the near future. The profile includes data on kindergarten readiness, 3rd grade measures, child care capacity and information on the quality rating improvement system, and early childhood indicators on family, health, and social services.

The community profile contains data specific to public health, such as data on the Health Access Nurturing Development Services (HANDS) home visitation program, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and the First Steps early intervention program for children with developmental disabilities. Data from HANDS

Figure 1: Kentucky Center for Education and Workforce Statistics Early Childhood Profile – Statewide, Page 1

Title V Data Integration Toolkit

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

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

What's the Purpose of a Data Story?



DEMONSTRATE A
SUCCESS



DEMONSTRATE A
PROGRAM/SERVICE NEED



DEMONSTRATE AN
INFORMATION
NEED



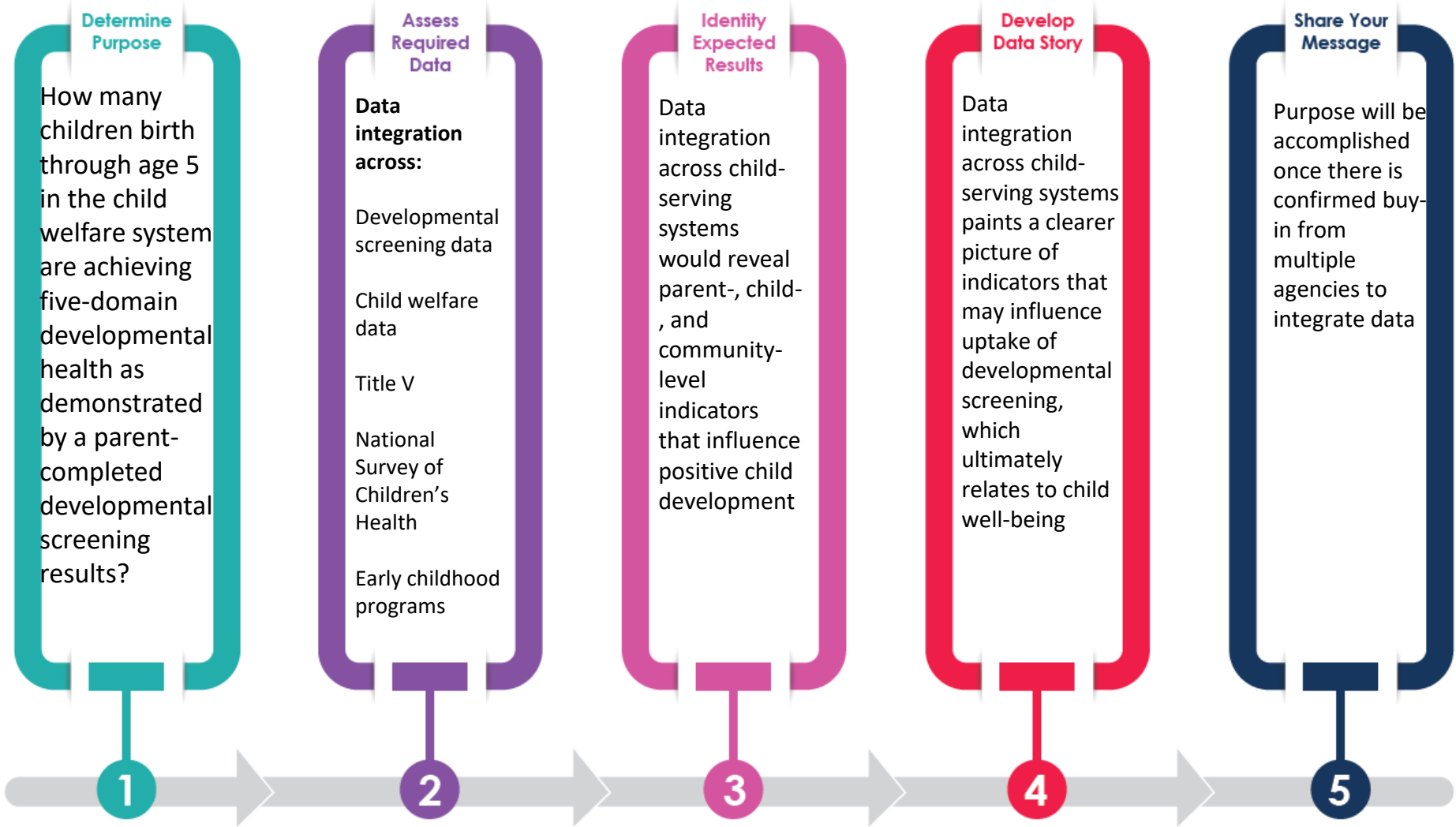
STATE A
GOAL/PRIORITY



EXAMINE A TREND



MEASURE PROGRESS
TOWARD A
PERFORMANCE TARGET



- *Over the next 10-15 minutes, work independently or in a group on the Data Story template in your packets. You can choose:*
 - *A real example from your work*
 - *A new idea related to integrating child welfare data into ECIDS & Title V*
- OR**
- *A made-up idea*



Share-Out



AMCHP

Small-Group Discussion

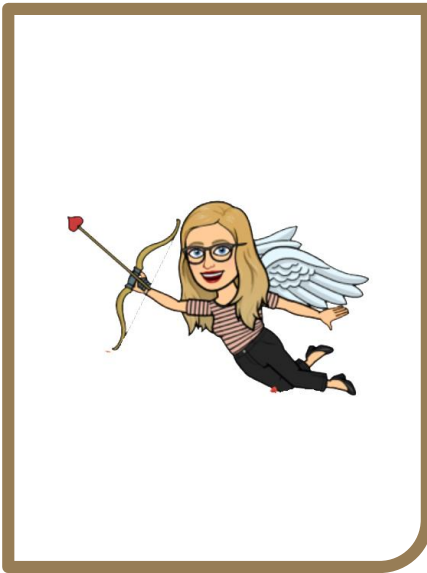
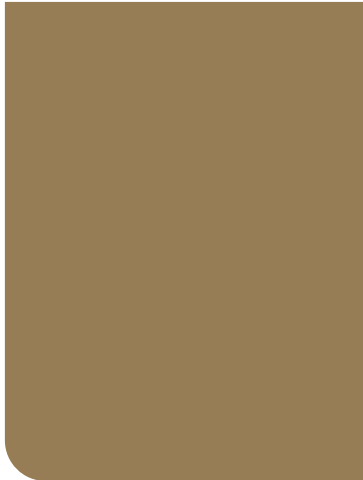
Discuss at your seats the following questions:

- **What work is your state/organization doing with child welfare data that can utilize early childhood or health data through integration?**
- **How will you use the toolkit/resources with your colleagues and partners?**

Share-Out



AMCHP



What's Next?

AMCHP Data Integration
technical assistance pilot

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

REMEMBER: AMCHP can be
your “cupid” to support building
connections

We'd love to hear your feedback!

Please complete the evaluation and place face-down at seat upon leaving





ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

SPHARC

State Public Health Autism Resource Center

www.amchp.org/SPHARC

Follow us on Twitter [@AMCHP_GrowingUp](https://twitter.com/AMCHP_GrowingUp)

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