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

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

Next stop: 2020!
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.
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
Every 5 years, states conduct a needs assessment to prioritize MCH needs.

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.

Next stop: 2020!
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 Theory of Change**

**NATIONAL NETWORK**

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**If**
through HMG, we engage key state leaders in the early childhood sector

**Then**
there will be greater alignment of partners toward a shared vision

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**If**
we build affiliate capacity to implement the HMG model with fidelity

**Then**
we will promote scale and spread of HMG

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**If**
affiliate sites engage in effective outreach of family, community, and child health partners

**Then**
children and families will have increased access to a more efficient and effective system

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**So that**
We advance developmental promotion, early detection and linkage to services to support optimal child development and child well-being

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HMG Affiliation
NPM 6 & HMG Affiliate Alignment
Title V MCH Programs
How does AMCHP provide support to states in addressing Developmental Screening?

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

1. Training
Training

Resources

eLearning

Publications

AMCHP
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

http://bit.ly/2tgAz3A
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
Learn the Signs. Act Early. (LTSAE)

State Systems Grant Outcomes
2011-2019

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
- 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

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
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)*
Why are states creating ECIDS?

- Articulate access and availability
- Standardization of data elements, formats and processes
- Transparency through aggregation and reporting of standardized data
- Management through automation, analytics and return on investment
- State and federal reporting requirements
- Demonstrate cross-program decision-making

AMCHP
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.

Examples of Current Health Data Integration

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

And Now.....
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 questions: 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 Daily Center's Early Childhood Data System Framework: Stakeholder Engagement
- Communications Plan Template
- How to Get Real Buy-in for Your Idea
- Three Strategies for Insuring Leadership Buy-in

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

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](https://nces.grads360.org/#program/about-the-sst)
Email: Support@sst-slds.org
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/
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.
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.
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.
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
What’s Next?

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
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

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