Assessing CYSHCN Programs Across the Nation: A Visual Profile of State CYSHCN (308050)

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Children with Special Health Care Needs: Treatment Models and Service Systems (4053)

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Presenter Disclosures

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(1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
What is AMCHP?

The Association of Maternal & Child Health Programs is a 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.
AMCHP Programs: CYSHCN

• National Consensus Framework for Improving Quality Systems of Care for CYSHCN – Standards Development and Implementation
• Leadership Institute for State Title V CYSHCN Directors (LICD)
• State Public Health Autism Resource Center
• Learn the Signs Act Early State Systems Grants
Learning Objectives

• Compare State Title V CYSHCN programs across the nation.
• Identify national trends and emerging issues related to State Title V CYSHCN programs.
Background

**How Many Children in the United States Have Special Health Care Needs?**

National Percent: 19.8% (14.6 million children)

2011-2012 National Survey of Children’s Health

**Children with qualifying responses on one or more of the five CSHCN Screener criteria**
Background

• Title V of the Social Security Act is a federal MCH block grant program that requires states to facilitate a system of services for CYSHCN

• Creating quality systems of care for CYSHCN is one of the most challenging and pressing priorities for CYSHCN leaders.

• State Title V CYSHCN programs have widely varying approaches to systems of care (i.e. direct services vs. population health)

• There is a need to understand the shared national vision for State Title V CYSHCN programs
Background

• Survey was conducted as part of the Leadership Institute for Title V CYSHCN Directors project

• Funded through the Lucile Packard Foundation for Children’s Health
Methods

• Online questionnaire: primarily multiple choice questions; some open-ended; 16 items
  – the role of State Title V CYSHCN programs
  – program eligibility
  – significant policy changes
  – health reform
  – system strengths and challenges

• Conducted in late 2013

• Respondents: State Title V CYSHCN Program Directors (29)
RESULTS
The Role of State Title V Program in CYSHCN System (Check all that apply) (N=29):

- Provide Care Coordination: 25 (86.2%)
- Family Support Services: 24 (82.8%)
- Enabling Services (i.e. transportation, respite care, family support services, etc.): 20 (69.0%)
- Quality Improvement and Monitoring: 16 (55.2%)
- Pay for Clinical Health Care Services (i.e. reimbursement): 16 (55.2%)
- Provide Clinical Health Care Services (i.e. administer a clinic): 15 (51.7%)
- Support for Durable Medical Equipment: 14 (48.3%)
- Other (please describe): 12 (41.4%)
State Title V CYSHCN Program Eligibility

- Diagnosis-Based: 14 (48.3%)
- Income-Based: 12 (41.4%)
- Age Criteria: 16 (55.2%)
- All CYSHCN Eligible: 17 (58.6%)
- Other: 4 (13.8%)
Governing State Laws or Rules

Is the State Title V CYSHCN program governed by a state law or rule that specifies what the program should do and who the program should serve? (N=29)

- Yes: 23 (79%)
- No: 6 (21%)
Within the past year, has your department/agency, executive branch, or legislative branch made significant policy changes that affect your State Title V CYSHCN program's work or everyday functioning? (N=29)

- Yes: 20 (69%)
- No: 9 (31%)
Regarding Medicaid Managed Care arrangements and CYSHCN, where is your state currently? (N=19)

- 8 (42%) CYSHCN in my state have already been moved into Medicaid Managed Care arrangements.
- 6 (32%) Currently moving CYSHCN into Managed Care arrangements.
- 2 (10%) Planning to move CYSHCN into Medicaid Managed Care arrangements (i.e. early discussions at the state level).
- 3 (16%) Considering moving CYSHCN into Medicaid Managed Care arrangements.

8 (42%)
Did State Title V CYSHCN Program participate in the development of insurance exchanges? (N=28)

My state did not develop a state exchange system and is using the federal exchange system.

- Yes: 6
- No: 16

(N=28)
CYSHCN System Strengths (N=29)

- Strong Title V Role in larger CYSHCN system: 18
- Strong policy and advocacy for CYSHCN: 11
- Strong executive support for Title V CYSHCN: 17
- Use of system standards: 10
- Efficient financing systems: 15
- Enhanced data capacity: 10
- Program continuity and sustainability: 18
- Innovative programs that address cultural...: 9
- Strong key partnerships: 28
- Strong family involvement: 26
CYSHCN System Challenges (N=29)

- High staff turnover: 16
- Meaningful family involvement: 18
- Uncertainty about future of Title V: 27
- Program continuity and sustainability: 24
- Addressing cultural competency: 19
- Proving value of Title V CYSHCN: 24
- Developing partnerships: 16
- Geographical challenges: 29
- Title V Role in larger CYSHCN system: 17
- Challenges in reimbursement/financing: 24
- Access to pediatric subspecialists: 26
Conclusions

• Most responding Title V programs provide enabling services (care coordination, family support, etc.)

• In many states, CYSHCN covered by Medicaid are in or moving to managed care arrangements

• Greatest system strengths include family involvement and strong partnerships

• Greatest system challenges include access issues (i.e. pediatric subspecialists) related to geography and uncertainty about the future of Title V
Next Steps

• Additional surveys of State Title V CYSHCN Directors:
  – Family involvement
  – In-depth exploration of system challenges and strengths as Title V Block Grant Transformation occurs

• Promoting and assisting with implementation of CYSHCN Standards in states
Thank You!

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