National Title V CYSHCN Program Profile: Results, Analysis, and Strategic Implications

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Sunday, March 5, 2017
10:30-11:30AM
Learning Objectives

• Increase understanding and awareness of state Title V CYSHCN Programs
• Understand trends, strengths and challenges of CYSHCN Programs
• Discuss opportunities for technical assistance opportunities to address challenges, expand understanding
Background

• Approx. 11.2 children under 18 yrs (20%) in U.S. have a special health care need
• Title V MCH block grant provides funding for family-centered, community-based, coordinated care for CYSHCN
• Expertise in reaching CYSHCN populations, data on service needs of CYSHCN and their families, connections to pediatric specialists
Changes Affecting CYSHCN Programs

• Rapidly changing health care environment
  • e.g., service delivery system, new payment models
• Shifts of CYSHCN population to managed care arrangements
• Changing role of Title V MCH/CYSHCN programs
• Policy and regulatory opportunities
• National Standards
• Block Grant Transformation
Purpose of CYSHCN Profile

• Increase understanding & awareness of CYSHCN programs (in light of changing context)
• Demonstrate value and leadership of CYSHCN programs
• Identify areas to support state CYSHCN programs
Methods

• SurveyMonkey link sent out via list serve or direct email to all CYSHCN programs
• N=48 total CYSHCN Programs – 46 states, DC, and 1 territory
• Analysis:
  • SAS v9.4
  • Univariate statistics: frequencies and percentages
  • Cross tabulations: examine relationships between variables
<table>
<thead>
<tr>
<th>Eligibility criteria is used to determine Title V CYSHCN program eligibility</th>
<th>Program has a process to identify CYSHCN?</th>
</tr>
</thead>
<tbody>
<tr>
<td>CYSHCN Program location</td>
<td>The role of the State Title V program in CYSHCN</td>
</tr>
<tr>
<td>Significant policy changes that affect your program's work or every day functioning</td>
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</tr>
<tr>
<td>Significant policy changes that affect your program's work or every day functioning</td>
<td>Tenure of Title V Director</td>
</tr>
<tr>
<td>Title V has an updated MOU with Medicaid that specifies areas of coordinated work related to implementation of the ACA for MCH/CYSHCN</td>
<td>CYSHCN program has established working relationships with your state’s Medicaid Director</td>
</tr>
<tr>
<td>The role of the State Title V program in CYSHCN</td>
<td>My state is a leader in:</td>
</tr>
<tr>
<td>Title V CYSHCN Program's level of collaboration with the different entities</td>
<td>My state is a leader in:</td>
</tr>
<tr>
<td>The role of the State Title V program in CYSHCN</td>
<td>Title V CYSHCN programs involvement in transition and medical home</td>
</tr>
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</table>
Results: Overview

- **Structure of programs** (location, role, legislation, affect of policy changes)
- **Tenure of director**
- **Role in System of Care** (eligibility criteria, medical home, transition, Program Strengths)
- **Partnerships** (including family engagement)
- **Financing of Care**
- **Emerging Issues** (implementing standards, areas to improve leadership)
Structure of CYSHCN Programs

- Location
- Legislation
- CYSHCN Program
- Policy Changes
- Role
Location of CYSHCN Programs

- Other (10%)
- Within Title V (58%)
- Separate Division from Title V (17%)
- Separate Agency from Title V (15%)
Role of State CYSHCN Programs

- Family support services: 40
- Enabling services (transport, respite...): 35
- Provide care coordination: 34
- Quality improvement and monitoring: 31
- Support durable medical equipment: 31
- Pay for clinical health care services: 26
- Pay for care coordination: 20
- Provide direct, clinical health care...: 16

# State CYSHCN programs serving in this role
Legislation/Policy Changes

• 27 states – role of CYSHCN program and population it serves are prescribed by state law or rule

• 14 indicated recent policy changes affected programs work or functioning, e.g.:
  • Transition to Medicaid Managed Care
  • Reduction in availability of Medicaid funds
  • Regionalization of CYSHCN services
  • Staff attrition
Tenure of CYSHCN Directors

Years in Current Role as CYSHCN Director

- <1 year: 13
- 1-3 years: 14
- 4-7 years: 15
- 8+ years: 6

<1 year 1-3 years 4-7 years 8+ years
CYSHCN Role in the System of Care
Eligibility determinations for CYSHCN Programs

- Age: 31%
- Diagnosis: 28%
- All CYSHCN are eligible: 27%
- Income: 24%
- Other: 18%
### Role in Medical Home

<table>
<thead>
<tr>
<th>The majority of respondents reported they:</th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Shared oversight and responsibility</strong></td>
<td>Strategically engage and partner with key groups in promoting and advancing the importance of a medical home</td>
</tr>
<tr>
<td></td>
<td>Provide technical assistance, expertise and support in medical home systems planning, development, and evaluation.</td>
</tr>
<tr>
<td></td>
<td>Provide expertise on the unique needs of CYSHCN in the development and implementation of medical home demonstration projects and other related efforts.</td>
</tr>
<tr>
<td></td>
<td>Assure medical home efforts are linked and integrated with other state level efforts.</td>
</tr>
<tr>
<td><strong>Aware but not taking the lead</strong></td>
<td>Use payment policy to incentivize and improve access to medical homes for CYSHCN.</td>
</tr>
<tr>
<td></td>
<td>Provide financial support for care coordination.</td>
</tr>
<tr>
<td></td>
<td>Adopt medical home qualification criteria and/or requirements on established models.</td>
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<td></td>
<td>Implement a process to identify clinical practices that meet expectations.</td>
</tr>
</tbody>
</table>
## Role in Transition

### The majority of respondents reported they:

<table>
<thead>
<tr>
<th>Shared oversight &amp; responsibility</th>
<th>Developing transition policies to share with key partners.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Educating all CYSHCN staff about health care transition best practices.</td>
</tr>
<tr>
<td></td>
<td>Identifying transitioning youth and enrolling in a transition registry.</td>
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<tr>
<td></td>
<td>Assessing and tracking readiness for adult health care with youth and families.</td>
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<tr>
<td></td>
<td>Setting performance expectations and/or implementing a process to identify clinical practices that meet expectations.</td>
</tr>
<tr>
<td></td>
<td>Evaluating program performance of transition programs.</td>
</tr>
<tr>
<td></td>
<td>Provide technical assistance, expertise and support</td>
</tr>
<tr>
<td></td>
<td>Providing expertise on the unique needs of CYSHCN</td>
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<td></td>
<td>Assuring that transition efforts are linked and integrated with other state level efforts.</td>
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</table>
Program Strengths

- Developing collaborations
- Advocating for CYSHCN programs
- Addressing cultural competency
- Reimbursement & financing
- Family Engagement
- Communicating the value of CYSHCN
- Use of National Systems Standards
- Financial capacity
- Understanding policies
- Developing CYSHCN workforce
- Data capacity
## Partnerships

<table>
<thead>
<tr>
<th>Level</th>
<th>Partnership Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td><strong>No partnership exists</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td><strong>Networking</strong></td>
<td>(Loosely defined roles, little communication, independent decision-making)</td>
</tr>
<tr>
<td>2</td>
<td><strong>Cooperation</strong></td>
<td>(Somewhat defined roles, formal communication, independent decision-making)</td>
</tr>
<tr>
<td>3</td>
<td><strong>Coordination</strong></td>
<td>(Share resources, defined roles, frequent communication, joint decision-making)</td>
</tr>
<tr>
<td>4</td>
<td><strong>Coalition</strong></td>
<td>(Share resources, frequent and prioritized communication, joint decision-making)</td>
</tr>
<tr>
<td>5</td>
<td><strong>Collaboration</strong></td>
<td>(Frequent communication and mutual trust, consensus reached on all decisions)</td>
</tr>
</tbody>
</table>
Collaborations with Key Stakeholders

- MCH Program/Agency/Counterpart: 4.41
- Family-to-Family Health Information: 3.74
- Key stakeholders consortia and/or...: 3.3
- Children's Hospitals/Systems: 3.22
- Other State Dept. of Health divisions, ...: 3.09
- Medicaid: 2.78
- Direct service providers: 2.76
- Provider groups (i.e. AAP): 2.7
- State Education Agency: 2.39
- Child Welfare and Social Services: 2.28
- Federally Qualified Health Centers: 1.67
- Health Plans: 1.57
- States with similar programs/models: 1.39

Mean Partnership Rating
Family Engagement in CYSHCN Programs

- Participate in MCH Block Grant & Needs Assessment activities: 4.56
- Serve on general program advisory groups and committees: 4.32
- Provide input on program activities: 3.96
- Serve on multi-disciplinary teams that provide direct services: 3.45
- Advocated on MCH issues, funding and legislation: 3.4
- Comment or act on proposed legislation: 3.3
- Manage programs or projects: 3.09
- Assist in MCH policy development beyond CYSHCN program: 2.91

Mean Rating
Financing of Care

• 16 reported CYSHCN staff participate in regular interagency meetings related to health care reform
  • 7 were unsure

• 12 reported that their state had an updated Title V/Medicaid MOU
  • 8 were unsure if an MOU existed
CYSHCN Program Use and Implementation of the Standards

- Written into Title V Block Grant
- Shared with partners
- Framework to convene stakeholders
- Incorporated into contracts
## Areas for leadership growth

<table>
<thead>
<tr>
<th>Mean Ratings of Selected Activities</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementing new reimbursement and financing systems for CYSHCN.</td>
<td>3.04</td>
</tr>
<tr>
<td>Garnering support for Title V CYSHCN in state executive branch.</td>
<td>3.31</td>
</tr>
<tr>
<td>Garnering support for Title V CYSHCN in state legislative branch.</td>
<td>3.31</td>
</tr>
<tr>
<td>Data capacity (i.e., LEND programs, registries).</td>
<td>3.39</td>
</tr>
<tr>
<td>Garnering support for Title V CYSHCN in the private sector.</td>
<td>3.40</td>
</tr>
<tr>
<td>Maintaining the financial capacity of the CYSHCN Program.</td>
<td>3.51</td>
</tr>
<tr>
<td>Programming which addresses cultural competency.</td>
<td>3.57</td>
</tr>
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Conclusions

- Insight into CYSHCN program structure and roles across the U.S.
- Identifies areas of program strengths
- Identifies areas to develop capacity to address a range of challenges
Next Steps

• Full report released by end of March 2017
• Opportunities for further analysis
• Inform future technical assistance and support to states
Questions?

• What else would you like to know?
• What does the data tell you in terms of opportunities for next steps?
Thank you!

For more information, visit:
http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx

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