April 2017

National Title V Children and Youth with Special Health Care Needs Program Profile

EXECUTIVE SUMMARY

Children and youth with special health care needs (CYSHCN) are a diverse group, ranging from children with chronic conditions to those with more medically complex health issues, to children with behavioral or emotional conditions. Within each state and territory in the U.S., the Title V Maternal and Child Health (MCH) and CYSHCN programs are charged with providing family-centered, community-based coordinated care. Although several state programs provide services for CYSHCN, the Title V CYSHCN programs are valued for their expertise in reaching CYSHCN populations, strong connections to networks of pediatric specialists, and high-quality data on the service needs of CYSHCN and their families.

Title V CYSHCN programs and their leadership face strategic decisions about their roles and responsibilities due to recent programmatic and policy influences. With the advent of new health care delivery models and other changes resulting from the Affordable Care Act (ACA), many state Title V CYSHCN programs are moving away from their more traditional role of providing direct health care services to the provision of wrap-around services and supports, and some payment for services not covered by Medicaid or private insurance, among other activities. The recent transformation of the Title V Block Grant and its new performance measurement system has led to restructuring and reframing of CYSHCN programs. Furthermore, some state Title V CYSHCN programs are assuming new roles in standards setting as the CYSHCN in their programs are moved into managed care arrangements.

The need for state Title V CYSHCN directors to network and consult with fellow state directors and reach out to CYSHCN experts has never been greater. In 2015-16, the Association of Maternal & Child Health Programs (AMCHP) fielded a CYSHCN Profile survey to gain insight into Title V CYSHCN programs across the U.S., including program structure and strengths, roles in systems of care, CYSHCN program partnerships, financing of care for CYSHCN populations and emerging issues for CYSHCN programs.

Profile Results

Forty-eight (48) state and territorial (hereafter referred to as "state") CYSHCN programs, including the District of Columbia, responded to the profile survey.[1] In the majority of states, the CYSHCN program is located within the Title V Maternal and Child Health program. The role of the CYSHCN program varies, with a smaller number continuing to provide direct services to children who do not have access to specialty care, and the majority transitioning to a focus on support services and systems development efforts.

Two major roles for CYSHCN programs are supporting medical home development and support services for transitioning CYSHCN to adult health care systems. In general, state CYSHCN programs do not have sole oversight related to medical home development efforts. In the areas of using payment policy to create **incentives** for and improve access to medical homes, providing **financial support** for care coordination, adopting **criteria and requirements** for established medical home models, and implementing processes to identify clinical practices that meet these standards, the majority of CYSHCN programs are aware of activities taking place in their states but are not leading the efforts. In the areas of developing **partnerships** to advance the importance of medical home, providing **expertise** on the unique needs of CYSHCN, assuring that medical home efforts are **linked** with other state activities, and offering **technical assistance** to support the development of medical homes, the majority of CYSHCN programs share oversight and responsibility.

In the area of transition to adulthood for adolescents and young adults, state CYSHCN programs are much more likely to have a leadership role within their states. The majority of CYSHCN programs report that they either share oversight and responsibility or have sole responsibility for:

- Overseeing the development of transition **policies**
- Educating staff about **best practices** in transition services

[1] *While the survey response group includes both state and jurisdictional CYSHCN programs, the term "state" is used broadly throughout the report.*

- **Assessing and tracking** youths' readiness for transition
- Setting and evaluating **performance expectations** for providers
- Providing **technical assistance** and support in transition planning
- Providing **expertise** on the unique needs of CYSHCN in the development of transition projects
- Assuring that transition efforts are **linked** with other state activities for CYSHCN

Respondents were asked to rate their programs' leadership in a range of areas, including programmatic roles, financing, advocacy, partnership development, and capacity development. Strong leadership ratings were reported in the areas of **communicating** the role and value of CYSHCN in MCH systems, **family engagement**, and developing **collaborations** with key partners. States were almost as confident in their leadership in the areas of developing CYSHCN **workforce capacity** within the state Title V agency, use of the **National Systems Standards** for CYSHCN, **advocating** for CYSHCN programs and supportive policies, and **understanding** policies that affect CYSHCN.

Developing partnerships and collaborating with stakeholders to build better systems of care for CYSHCN is a key strength for CYSHCN programs. Of the stakeholders listed on the survey, the **MCH agency** was the one with the strongest reported partnership with the CYSHCN program, and **Family-to-Family Health Information Center** was another close partner. **Coordination** with key stakeholder groups, such as consortia or committees, and with state health departments was also strong.

Respondents were asked to rate various aspects of their programs' engagement with families and consumers. Families appear to be most engaged in **programmatic and advisory** roles, such as participation in the development of the Block Grant and needs assessment, serving on general program advisory groups and committees, and providing input on program activities. Many CYSHCN programs also engaged families in advocacy on MCH issues, and commenting on proposed legislation. These results are consistent with a 2014-2015 survey that AMCHP conducted on family engagement policies and practices in Title V MCH and CYSHCN programs - *Sustaining and Diversifying Family Engagement in Title V MCH and CYSHCN Programs.*[1]

Although state CYSHCN agencies recognize the importance of partnerships with Medicaid, CHIP, and state insurance agencies, many responses indicated collaboration could be improved. Some of the areas in which respondents rated their leadership on the lower end of the scale included reimbursement and financing systems, garnering support for their programs within state government and the private sector, data capacity, financial capacity, and cultural competency. Nevertheless, the survey demonstrated opportunities for Title V CYSHCN programs to take a leadership role in **policy**, **advocacy**, and **financing** systems for CYSHCN.

Clearly, state CYSHCN programs face a range of challenges, both internal and external, as the transformation of the health care system continues. It will be essential that these programs develop their capacity to contribute meaningfully to the challenges of financing and overseeing the quality of care for CYSHCN, in the forms of close partnership with public and private payers; leadership in data analysis, financing and advocacy; and involvement in development of the medical home and other clinical programs.

While the CYSHCN profile only provides a snapshot of CYSHCN programs and not trends over time, it does provide insight into CYSHCN program structure, strengths, partnerships, roles in systems of care, financing of care and emerging issues. In the future, the survey data will be further analyzed to develop resources to assist states in addressing challenges and advancing their CYSHCN programs. The profile results and further analysis allow states and territories to compare and improve CYSHCN systems of care and foster cross-state connections and spread of promising practices and strategies. These data will also be used to inform technical assistance opportunities to develop the capacity of CYSHCN programs. Additionally, the survey was designed to allow for assessment of CYSHCN programs over time, which allows the capacity for trends analysis in the future if the survey is repeated.



Background and History of CYSHCN Programs

In the United States, approximately 11.2 million children under the age of 18 have special health care needs.[2] Children and youth with special health care needs (CYSHCN) are a diverse group of children, ranging from children with chronic conditions to those with more medically complex health issues, to children with behavioral or emotional conditions. The Maternal and Child Health Bureau (MCHB) defines CYSHCN as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Within each state, the Maternal and Child Health (MCH) and CYSHCN program (known as the Title V program) is charged with providing family-centered, community-based coordinated care. Authorized by Title V of the Social Security Act, the MCH Services Block Grant supports the infrastructure for MCH in every state and territory. Consisting of the state MCH and CYSHCN programs, Title V supports efforts within the public and private sectors to shape and monitor health-related services for women, children and youth. Although several state programs provide services for CYSHCN, ideally, the Title V CYSHCN programs are valued for their expertise in reaching CYSHCN populations, maintaining their strong connection to networks of pediatric specialists, and having the high-quality data on the service needs of CYSHCN and their families. In 2015, nearly 4.2 million CYSHCN were served by Title V programs.[3]

State Title V CYSHCN programs have evolved over their 85-year history. Originally known as the Crippled Children's Services program when Title V of the Social Security was first enacted in 1935, the programs focused on clinical services for children with physical disabilities such as cerebral palsy, spina bifida and cystic fibrosis. In 1981, Title V and six other federal categorical programs were consolidated into the Maternal and Child Health Services Block Grant, as part of the Omnibus Budget Reconciliation Act of 1989. The law required that at least 30 percent of block grant funds be used for CYSHCN and mandated that CYSHCN programs assume a leadership role in the development of family-centered, community-based, coordinated systems of care. This led some states to move away from direct services and into more infrastructure building activities. In 1998, the MCHB adopted a broader definition of CYSHCN[4] and in 2001 launched the National Survey of Children with Special Health Needs to establish prevalence and monitor progress. MCHB also identified six quality indicators of a system of services[5] that have influenced state activities and state priorities:

- **Family Professional Partnerships**: Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
- **Medical Home**: CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.
- **Adequate Insurance and Financing**: Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.
- **Early and Continuous Screening and Referral**: Children are screened early and continuously for special health care needs.
- **Easy to Use Services and Supports**: Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.
- **Transition to Adulthood**: Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

The passage of the Patient Protection and Affordable Care Act (ACA) identified the Medical Home model as a standard of care for CYSHCN, with the intent of improving systems of care and coverage for CYSHCN, yet coverage gaps and systems fragmentation continues.

Recent Changes Affecting CYSHCN Programs

State Title V CYSHCN programs are at a crossroads as they face strategic decisions about their roles and responsibilities in the context of the implementation of the ACA. With the advent of new health care delivery models and the ACA, many state Title V CYSHCN programs are moving away from their more traditional role of providing direct health care services to the provision of wrap-around services and supports, and as a payor of last resort for services not covered by Medicaid or private insurance, among other activities. Furthermore, some state Title V CYSHCN programs are assuming new roles in standards setting as CYSHCN populations are moved into managed care arrangements.

National CYSHCN Systems Standards

For several decades, national reports, initiatives, and research have called for frameworks, standards, and measures to advance a comprehensive system of care for CYSHCN and their families. These efforts laid the foundation for important work in states and communities, health plans and practices. However, until the release of the 2014 National Standards for Systems of Care for CYSHCN, these efforts had not resulted in an agreed upon set of national standards that could be used and

applied within health care and public health systems to improve health quality and outcomes for this population of children.[6] The National Standards[7] provide a critically important framework that highlights specific system requirements for health providers and plans serving CYSHCN. Additionally, the National Standards offer operational and measurable guidelines for state systems of care serving CYSHCN. States are using the National Standards to make improvements in their health care service delivery systems serving CYSHCN. Title V CYSHCN programs in particular have made strides to incorporate the National Standards into their grant needs assessments and action plans, as well as provide leadership in standard setting and implementation.

Title V Block Grant Transformation

Since its original authorization, Title V of the Social Security Act has been revised several times to reflect the increasing national interest in maternal and child health and well-being. In recent years, budgetary constraints highlighted the need to demonstrate the effectiveness of government programs. The passage of the ACA also highlighted the need for evidence demonstrating how Title V programs play a unique role in improving the health of the nation's mothers, children and families. To develop a common vision for improving and transforming the Title V MCH Block Grant, MCHB engaged stakeholders, national, state and local leaders, families and other partners to improve accountability of performance and impact, and better demonstrate the return on investment for Title V in improving the health and well-being of mothers, children and families in the U.S.[8] In 2015, MCHB implemented the changes to the Title V program, including a new performance measurement system for the Title V Block Grant that increases state flexibility and reduces reporting burden for states by allowing them to choose National Performance Measures to target, and increases accountability by requiring states to develop actionable strategies and evidence-based/informed strategy measures.[9] Title V programs, including CYSHCN, are implementing these changes and restructuring programs to respond to the new performance measurement and reporting systems, as well as state priorities identified in recent five-year needs assessments.

The need for state Title V CYSHCN directors to network and consult with fellow state directors and reach out to CYSHCN experts has never been greater. The sheer number of new directors, as well as the restructuring of programs, pose a challenge. The CYSHCN Profile Survey provides a snapshot of CYSHCN programs across the U.S. and insights into program structure and strengths, roles in systems of care, CYSHCN program partnerships, financing of care for CYSHCN and emerging issues for CYSHCN programs.

Survey Methods

From December 2015 – April 2016, AMCHP conducted an electronic survey via Survey Monkey to increase understanding and awareness of Title V CYSHCN programs. The survey gathered information on key characteristics of each state's CYSHCN program. The survey was distributed via listserv and direct email to the Title V CYSHCN directors in each state and territory.

The survey results output was downloaded as a comma separated values (CSV) file and input into SAS version 9.4 for univariate and cross-tabulation analysis. Univariate analysis calculated frequency counts and percentages for answers to each survey question. Cross-tabulation analysis was used to investigate possible relationships between variables by displaying the frequency of respondents that have specific characteristics determined by two different survey questions. The contingency tables created through cross tabulation analysis were:

Cross-tabulation Analyses Performed

Survey Question – Variable 1	Survey Question – Variable 2
Eligibility criteria used to determine Title V CYSHCN program	CYSHCN program process to identify CYSHCN
CYSHCN program location	Role of the State Title V program in CYSHCN system
State policy changes that affect CYSHCN program's work or everyday functioning	Role of the State Title V program in CYSHCN System
State policy changes that affect CYSHCN programs' work or everyday functioning	Tenure of current Title V CYSHCN director
Updated Title V/Medicaid MOU that specifies areas of coordinated work related to implementation of the ACA for MCH/CYSHCN populations	Does your CYSHCN program know and have established working relationships with your state's Medicaid director?
Role of the State Title V program in CYSHCN system	Program leadership in programmatic roles, financing, advocacy, partnership development, capacity development, etc.
Role of the State Title V program in CYSHCN system	Title V CYSHCN program involvement in transition activities
Role of the State Title V program in CYSHCN system	Title V CYSHCN program involvement in medical home activities

Statistical testing for significance of the cross-tabulation analysis (chi-square, fisher's exact test) was not used due to small cell sizes and the fact that AMCHP had responses from each state. Therefore, the cross-tabulation analysis shows us the current state of CYSHCN programs throughout states at the point in time of the survey.

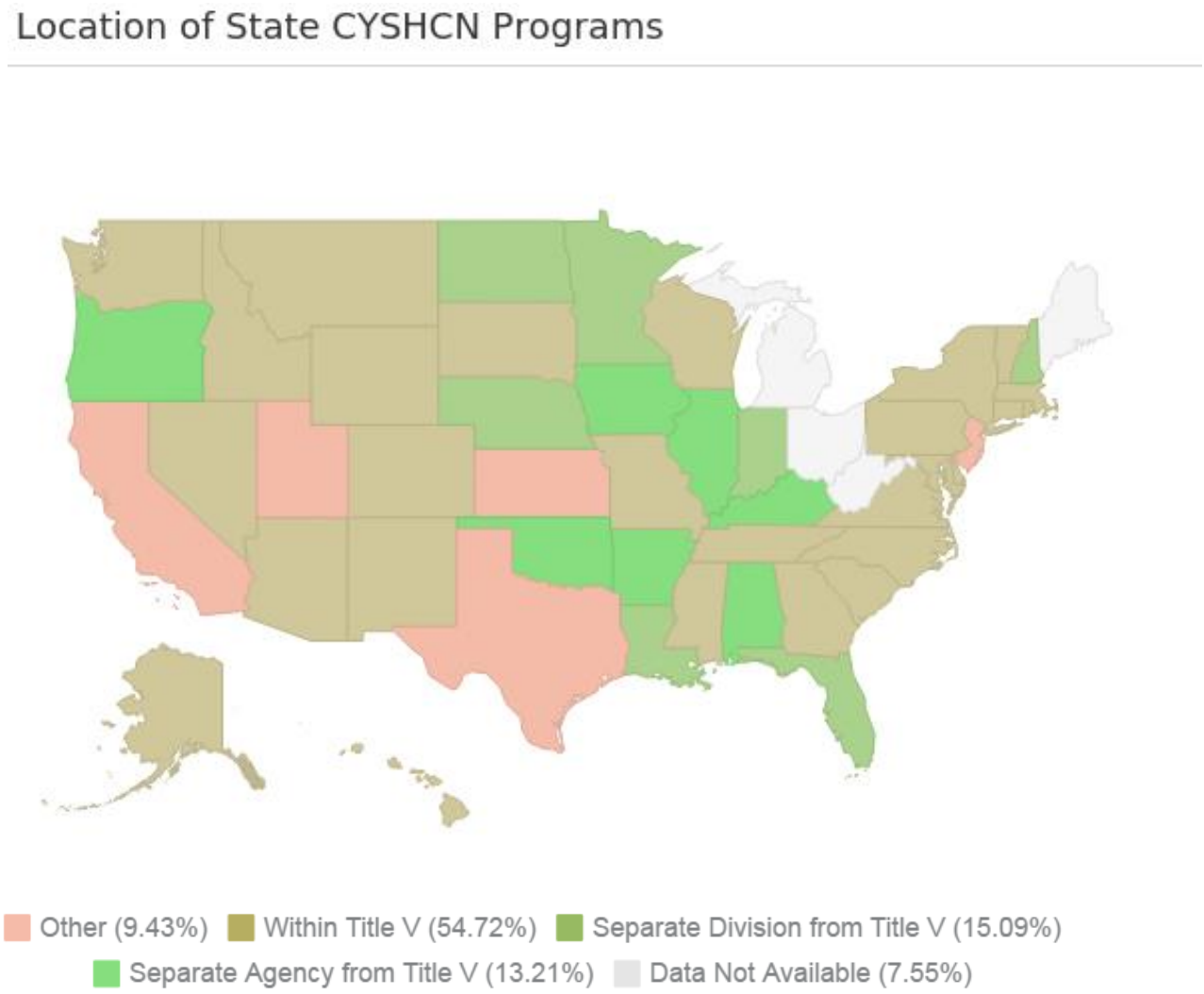
PROFILE RESULTS

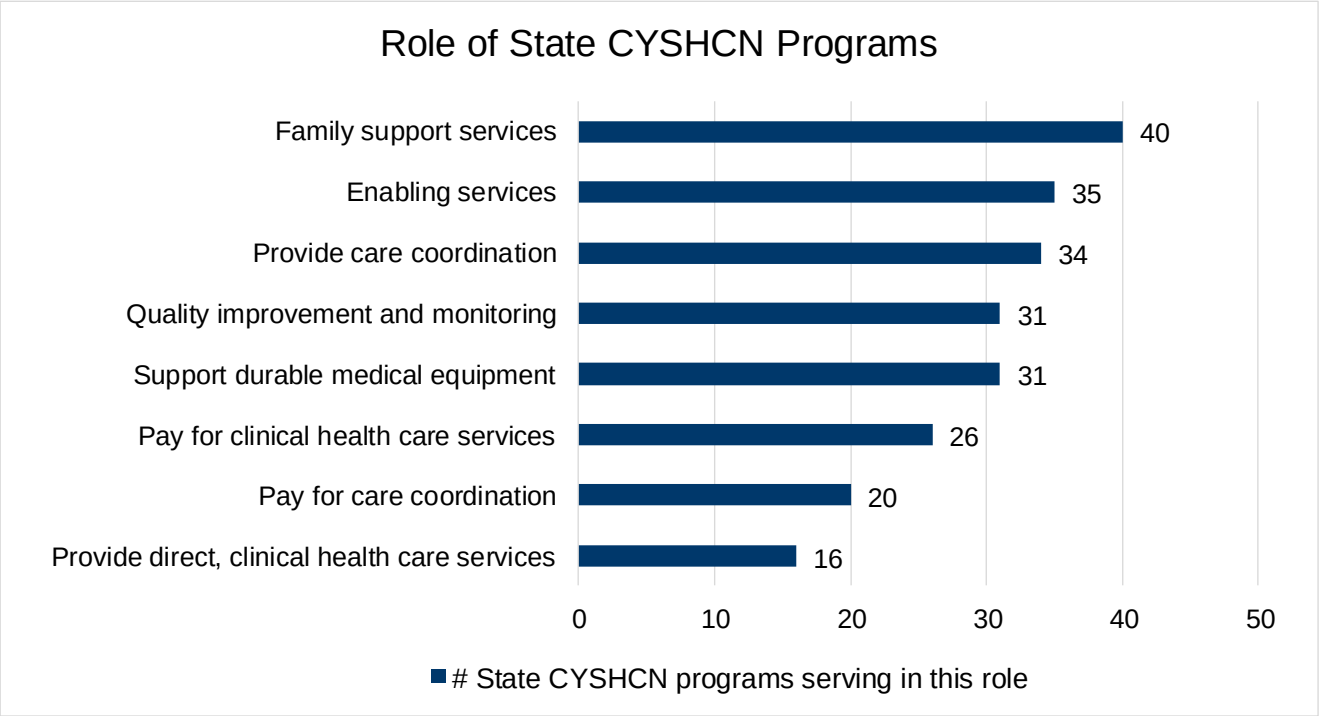
Responses were received from a total of 48 state and territorial CYSHCN programs (including the District of Columbia). Respondents were not required to answer every question in the survey. Where a large proportion of respondents did not answer a question, this is noted in the report. Results are summarized below.

I. Structure of Title V CYSHCN Programs

Every state has unique factors that contribute to the structure for its system of care for CYSHCN, including historical commitment to children with disabilities, the availability of specialty care throughout the state, and relationships with key constituencies, as well as financial and demographic issues. Within state government, state CYSHCN programs are located and structured differently, with several programs located outside the health department and/or in different divisions within the department.

In the majority of respondent states (28, including the Northern Mariana Islands), the CYSHCN program is located within the Title V Maternal and Child Health program. In another eight programs (including the District of Columbia), the program is located in a separate division, but in the same agency that houses the Title V MCH program. Seven states house the CYSHCN program in a separate agency from the MCH program, and five states noted another location for their CYSHCN program. It appears, however, that in most of these cases, the CYSHCN is in the same agency but a different division from MCH. One state, California, houses CYSHCN in the state Medicaid agency.





The role of the CYSHCN program in the states varies, with some continuing to provide direct services to children who do not have access to specialty care, while most focus on support services and systems development efforts. Of the 48 that responded to this question, 16 provide direct clinical services and 26 pay for these services; of these, 12 states both provide and pay for direct services. The provision and financing of support services is a more common role of CYSHCN programs. The support services facilitated by CYSHCN programs include:

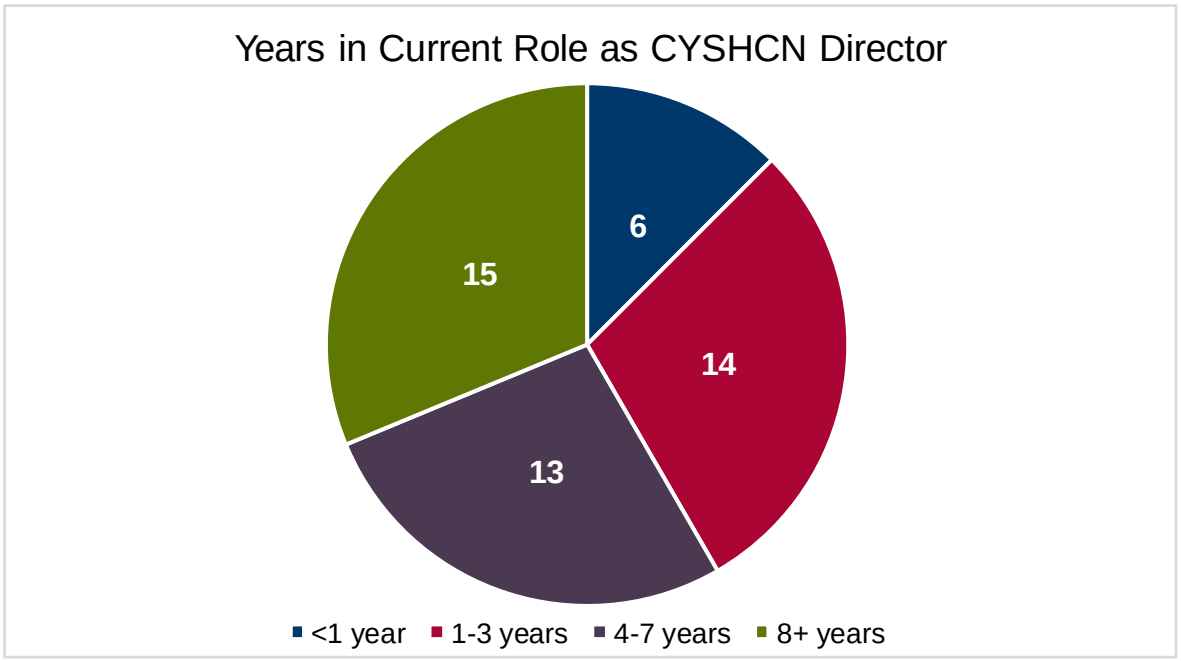
- Family support services (40 states);
- Enabling services, i.e. transportation, respite care, outreach, etc. (35 states).
- Care coordination (provided by 34 state programs and financed by 20, both provided and financed by 11); and
- Support for durable medical equipment, i.e., home health services, medical foods, etc. (31 states).

Quality improvement and monitoring is a role of 31 state programs, and 19 indicated that they provide other services than those listed. Other services included assistance with insurance premiums and co-pays, monitoring and evaluation of CYSHCN programs, pharmaceutical care coordination, systems development, outreach, and education. The location of the CYSHCN program does not appear to be related to the role of the program in providing or paying for services.

In 27 states, the roles of the CYSHCN program and the population it serves are prescribed by state regulation. In general, the regulations outline the purpose and activities of the CYSHCN program and may define the population that is eligible for the program. Some, like Virginia, use the federal definition of CYSHCN, while others, such as New York, contain a list of qualifying conditions. Florida's statute uses the federal standards of family-centered, comprehensive, coordinated, community-based care.

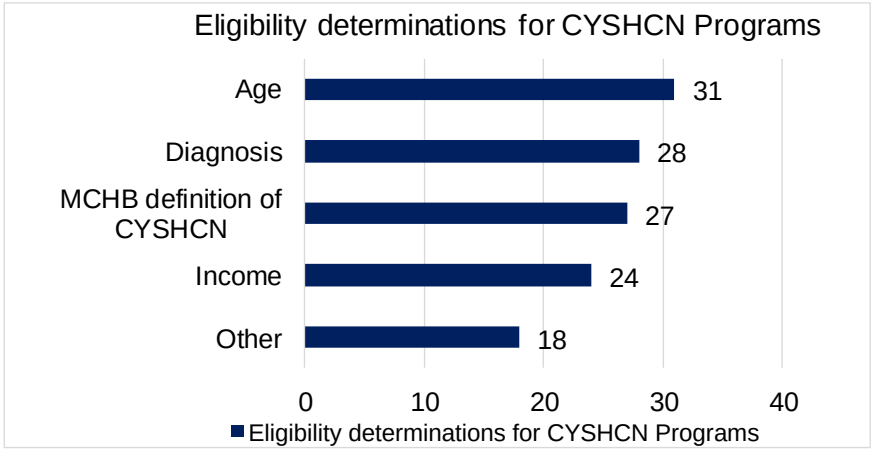
Fourteen states indicated that recent policy changes have affected their program's work or everyday functioning. Major changes mentioned by these states include the transition to Medicaid managed care for CYSHCN and the development of primary care medical homes; the state's decision not to participate in the ACA Medicaid expansion and losing the opportunity for additional Medicaid funds, regionalization of CYSHCN services, and loss of institutional memory and capacity due to staff attrition.

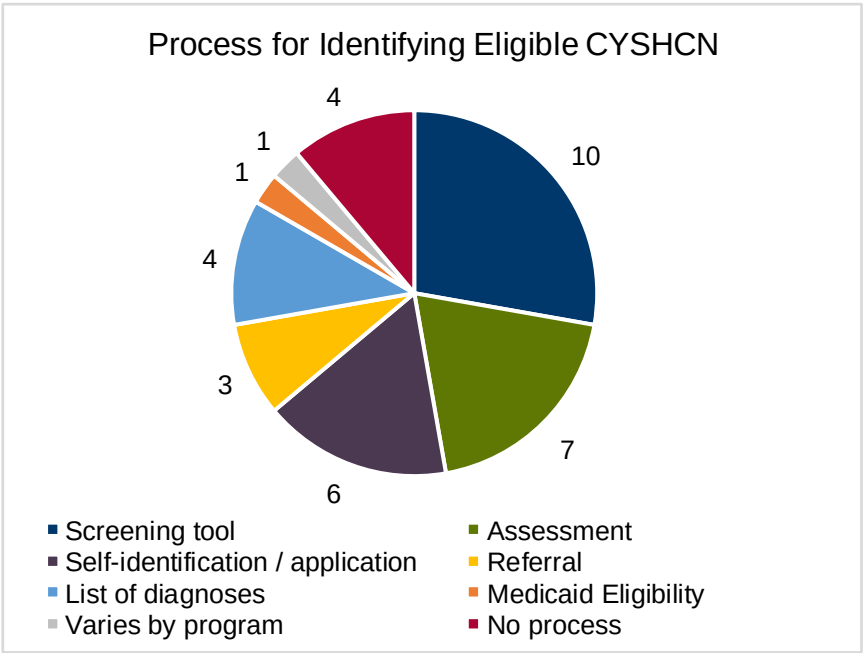
Many state CYSHCN directors are relatively new to their positions. Six states reported that their CYSHCN directors have been in their jobs for less than one year, and 14 have been there for one-three years. An additional 13 have been in place for four-seven years, while a total of 15 have been in their positions for eight or more years. Similarly, respondents indicated 29 state Title V directors have been in their positions for three years or less, while 8 have been there for four-seven years and 10 have been in their jobs for eight years or more.



II. System of Care

Eligibility for the CYSHCN program is based on diagnosis in 28 states, income in 24 states, and age in 31 states (states may use more than one of these criteria). Twenty-seven (27) states use the MCHB definition of CYSHCN to determine eligibility, and 18 indicated that they use other criteria. Children who are eligible for CYSHCN program services are identified using a CYSHCN screening tool in 10 states, using the national screening tool in four of these states, and with other methods in 35 states (no state reported using risk-based software to identify CYSHCN). Other methods included an assessment process (seven states), self-identification or an application process (six states), referral (three states), eligibility for Medicaid (the District of Columbia), a list of diagnoses (four states) and processes that vary by program (one state). Four states indicated that they did not have a process for identifying CYSHCN. Several states noted that because their programs focused on infrastructure building and systems development, no eligibility criteria or determination processes were needed. In most states (29), the eligibility determination process takes place within the Title V MCH program, but in 15 states it takes place in another agency.





A. Medical Home

In general, state CYSHCN programs do not have sole oversight in activities related to the medical home. In the areas of developing partnerships to advance the importance of medical home, providing expertise on the unique needs of CYSHCN, assuring that medical home efforts are linked with other state activities, and offering technical assistance and expertise to support the development of medical homes, the majority of CYSHCN programs share oversight and responsibility. In the areas of using payment policy to create incentives for and improve access to medical homes, providing financial support for care coordination, adopting criteria and requirements for established medical home models, and implementing processes to identify clinical practices that meet these standards, many CYSHCN programs are aware of activities taking place in their states but are not taking the lead. The areas in which CYSHCN programs are least likely to be involved at all are those relating to payment policy and the development of processes to identify qualified clinical practices.

CYSHCN Program Role in Medical Home*				
	Sole responsibility and oversight	**Shares oversight and responsibility**	**Aware but not taking lead**	**Not Involved**
Using payment policy to incentivize and improve access to medical homes for CYSHCN.	1	5	**26**	10
Providing financial support for care coordination.	3	15	**17**	7
Adopting medical home qualification criteria and/or requirements on models established by a national organization (i.e., NCQA).	1	9	**26**	5
Strategically engaging and partnering with key groups in promoting and advancing the importance of a medical home.	4	**25**	13	1
Implementing a process to identify clinical practices that meet expectations.	1	10	**22**	8
Provide technical assistance, expertise and support in medical home systems planning, development, and evaluation.	3	**23**	14	3
Providing expertise on the unique needs of CYSHCN in the development and implementation of medical home demonstration projects and other related efforts.	6	**20**	15	2
Assuring that medical home efforts are linked and integrated with other state-level efforts.	2	**23**	15	3

**Numbers indicate the number of states that selected each response. Bolded numbers indicate categories with the most responses.*

B. Transition to Adulthood

In the area of transition to adulthood for adolescents and young adults, state CYSHCN programs are more likely have a leadership role within their states. In every area, the majority of CYSHCN programs report that they either share oversight and responsibility or have sole responsibility for oversight in their states. These roles include development of transition policies, educating staff about best practices in transition services, assessing and tracking youths' readiness for transition, setting performance expectations for providers and evaluating their performance, providing technical assistance and support in transition planning, providing expertise on the unique needs of CYSHCN in the development of transition projects, and assuring that transition efforts are linked with other state activities for CYSHCN.

It should be noted that in some of these areas, a substantial number of states did not respond to the question about their roles. These include identifying current and future transitioning youth and enrolling in a transition registry (17 states did not respond) evaluating the performance of transition programs (17), setting performance expectations and/or implementing a process to identify clinical practices that meet expectations (12), and assessing and tracking readiness for adult health care with youth and families (10). This may indicate that these activities are not underway in these states.

CYSHCN Program Role in Transition to Adulthood*				
	Sole responsibility and oversight	**Shares oversight and responsibility**	**Aware, but not taking lead**	**Not Involved**
Developing transition policies to share with key partners.	6	**27**	9	1
Educating all CYSHCN staff about health care transition best practices.	**18**	**22**	3	0
Identifying transitioning youth (current/future) and enrolling in a transition registry.	5	**9**	**9**	8
Assessing and tracking readiness for adult health care with youth and families.	8	**17**	10	3
Setting performance expectations and/or implementing a process to identify clinical practices that meet expectations.	4	**13**	**13**	6
Evaluating program performance of transition programs.	4	**10**	9	8
Provide technical assistance, expertise and support in transition planning, development, and evaluation.	7	**28**	6	0
Providing expertise on the unique needs of CYSHCN in the development and implementation of transition projects and other related efforts.	10	**25**	5	1
Assuring that transition efforts are linked and integrated with other state level efforts.	7	**25**	6	3

** Numbers indicate the number of states that selected each response. Bolded numbers indicate categories with the most responses.*

C. Program Strengths

Respondents were asked to rate their programs' leadership in a range of areas, including programmatic roles, financing, advocacy, partnership development, and capacity development, on a scale of one (highly disagree that the CYSHCN agency is a leader) to five (highly agree). The mean rating across responding states was calculated; a mean higher than 3.0 indicates general agreement that the state is a leader, and a higher mean indicates stronger agreement.

In all areas, the mean exceeded 3.0. The lowest average ratings were seen in the areas of reimbursement, financing, and data capacity. Means above 4.0 were reported in the areas of communicating the role and value of CYSHCN in MCH systems, family engagement, and developing collaborations with key partners. States also had high confidence in their leadership in the areas of developing CYSHCN workforce capacity within the state Title V agency (mean of 3.72), use of the National Systems Standards for CYSHCN (3.74), advocating for CYSHCN programs and supportive policies (3.83), and understanding policies that affect CYSHCN (3.89).

The strength of CYSHCN programs' leadership in programmatic and capacity-building activities echo their assessment of their roles in the areas of the medical home and transition services; their responsibility for technical assistance, the provision of substantive expertise, and partnership development are demonstrated in their leadership in the areas of collaboration, communication, and advocacy.

CYSHCN Program Strengths	Mean (scale 5=Highly Agree; 1=Highly Disagree)
Implementing new reimbursement and financing systems for CYSHCN.	3.04
Data capacity.	3.39
Maintaining the financial capacity of the CYSHCN program.	3.51
Programming that addresses cultural competency.	3.57
Developing CYSHCN workforce capacity in state Title V agency.	3.72
Use of the National Systems Standards for CYSHCN.	3.74
Advocating for CYSHCN programs/supportive policy.	3.83
Understanding policies that affect CYSHCN.	3.89
Communicating the value/role of CYSHCN in MCH systems.	4.02
Family engagement in programs and initiatives.	4.21
Developing collaborations with key partners.	4.47

III. Partnerships

Developing partnerships and collaborating with stakeholders to build better systems of care for CYSHCN is a key strength for CYSHCN programs. As the survey respondents highlighted in both state self-reported strengths and as demonstrated in both Medical Home and Transition to Adulthood activities, state CYSHCN programs are the ultimate conveners to advance quality care for CYSHCN. Respondents ranked their partnerships with key stakeholders on a collaboration scale[10]:

- **No partnership exists: 0**
- **Networking** (Loosely defined roles, little communication, independent decision-making): **1**
- **Cooperation** (Somewhat defined roles, formal communication, independent decision-making): **2**
- **Coordination** (Share resources, defined roles, frequent communication, joint decision-making): **3**
- **Coalition** (Share resources, frequent and prioritized communication, joint decision-making): **4**
- **Collaboration** (Frequent communication and mutual trust, consensus reached on all decisions): **5**

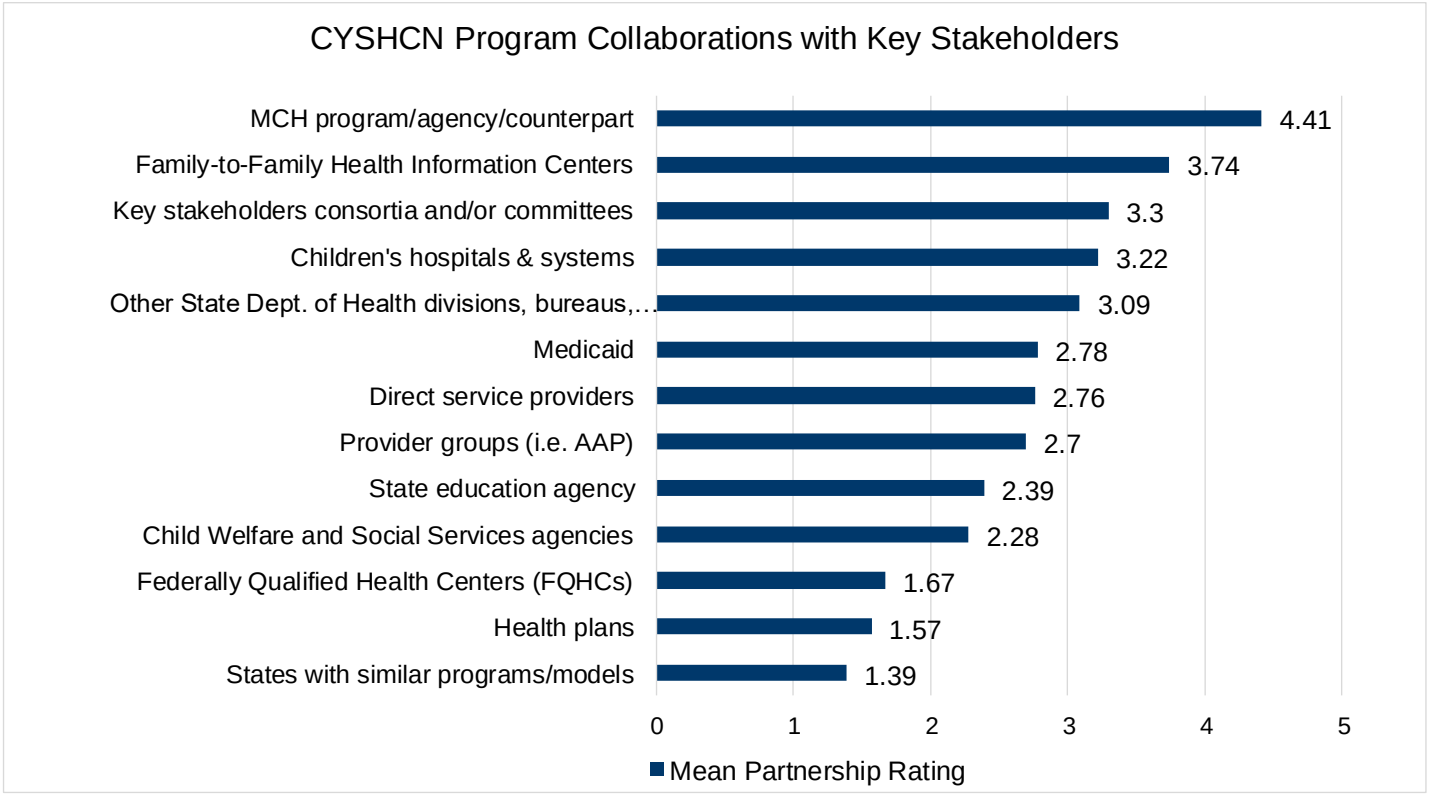
A. Collaborations with Key Stakeholders

Of the stakeholders listed on the survey, the MCH agency had the strongest reported partnership with the CYSHCN program, with 31 states reporting collaboration and an additional four reporting a coalition between the two agencies, for a mean rating of 4.41. Family-to-Family Health Information Centers were another strong partner, with 16 states reporting collaboration and 14 reporting a coalition, for a mean rating of 3.74. Coordination with key stakeholder groups, such as consortia or committees, was also high, with 13 states reporting collaboration and nine reporting coalitions, for a mean of 3.30. Partnerships within state health departments were also rated highly, with 14 states reporting coordination for a mean of 3.09.

The strength of partnerships with clinical providers and their oversight agencies and associations varied. The strongest such partnership was with children's hospitals and systems, which are the most likely to work specifically with CYSHCN and their families; the mean rating of these partnerships was 3.22. The mean rating for partnerships with other direct service providers was 2.76, for the AAP and other provider groups was 2.70, and for Federally Qualified Health Centers was 1.67, indicating that while these relationships are cooperative, they fall short of full coordination in most cases. In the case of health plans, the mean rating was 1.57, with 15 states reporting cooperation and 14 reporting networking. As health reform evolves, stronger coordination may be needed in this area.

Partnerships with other relevant state agencies were also variable. State CYSHCN programs' relationship with their state Medicaid agencies was fairly strong, with 18 states reporting cooperation and 11 reporting coordination, for a mean rating of 2.78. Partnerships with state welfare/social services and education agencies, both key stakeholders in systems of care for CYSHCN, were weaker, with means ratings of 2.28 and 2.39, respectively. In the case of state education agencies, 12 states reported coordination and 11 reported networking with this agency; for state welfare and social service agencies, 19 reported cooperation and 11 reported networking.

It is possible that state CYSHCN directors' tenure in their position influences their ability to develop partnerships with internal and external stakeholders. In many cases, the mean partnership rating was somewhat higher in states where the CYSHCN director has held the position for more than 10 years (n=9) than in states where the director has been in place for 10 years or less (n=38, with two of these states not responding to these questions). However, these differences were not consistent and were often not large.



Mean Partnership Ratings by Tenure of CYSHCN Director		
	Tenure of CYSHCN Director	
Potential Partner	*<= 10 years*	*>10 years*
States with similar programs/models	1.43	1.22
Health plans	1.54	1.67
Federally Qualified Health Centers (FQHCs)	1.73	1.44
Child Welfare and Social Services agencies	2.11	3.00
State Education Agency	2.30	2.78
Provider groups (i.e., AAP)	2.70	2.78
Direct service providers	2.83	2.44
Medicaid	2.78	2.78
Other State Department of Health divisions, bureaus, offices, or programs	3.03	3.33
Children's Hospitals/Systems	3.79	2.56
Key stakeholder consortia and/or committees (i.e., medical home advisory committees, condition-specific work groups, etc.)	3.24	3.56
Family-to-Family Health Information Centers	3.68	4.00
MCH program/agency/counterpart	4.32	4.78

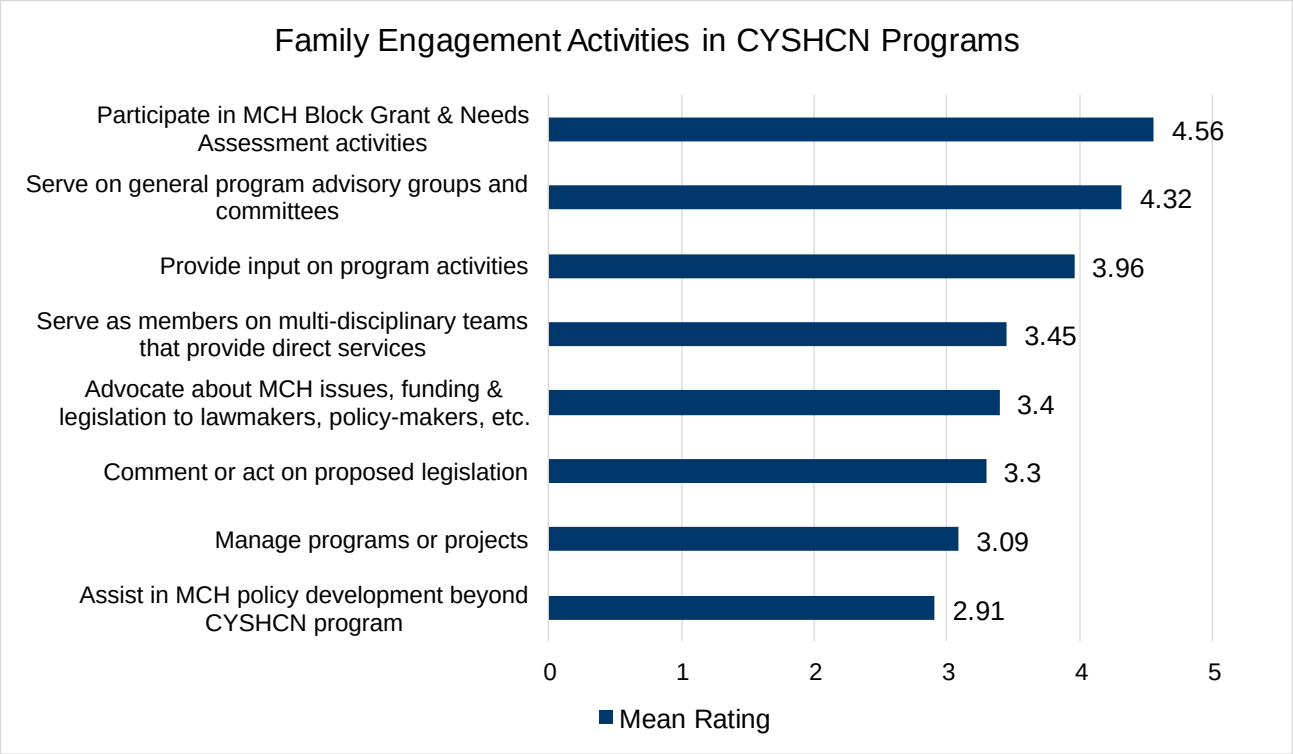
Respondents were also asked whether they or their staff knew and had established working relationships with specific staff within the state Medicaid and other health agencies, including the state Medicaid director, EPSDT staff, eligibility staff, and managed care staff. Just over half reported that these relationships exist; 27 have a relationship with the Medicaid director, 29 with EPSDT staff, 32 with eligibility staff, and 25 with managed care staff. Only five states said that none of these relationships exist, and one was unsure.

In the case of other state health officials, working relationships were not as common. Only 19 states reported a working relationship with the CHIP director and 21 with CHIP staff (although in many states the CHIP and Medicaid director may be the same person). In five states, respondents reported a working relationship with the Marketplace director and 12 with the Marketplace outreach and enrollment contact. Similarly, six states reported a working relationship with the Health Insurance Commissioner and 12 had a relationship with the ombudsman or the person responsible for grievances and appeals.

B. Family Engagement

Respondents were asked to rate various aspects of their programs' engagement with families and consumers on a scale of one (never) to five (always). Families appear to be most engaged in programmatic and advisory roles; the mean rating for families' participation in the development of the Block Grant and needs assessment was 4.56, and for serving on general program advisory groups and committees was 4.32. The mean rating for family engagement in advocacy on MCH issues was 3.40, for commenting on proposed legislation was 3.30, and for assistance in policy development was 2.91, indicating room for additional involvement of families on the policy and legislative level.

It should be noted that states' ratings of family engagement tended to cluster across categories, with few states reporting ratings that varied more than two points across categories. The states' overall means across the eight activities ranged from 2.0 to 5.0, indicating that some states have room for additional family engagement overall while others involve families consistently in their activities.



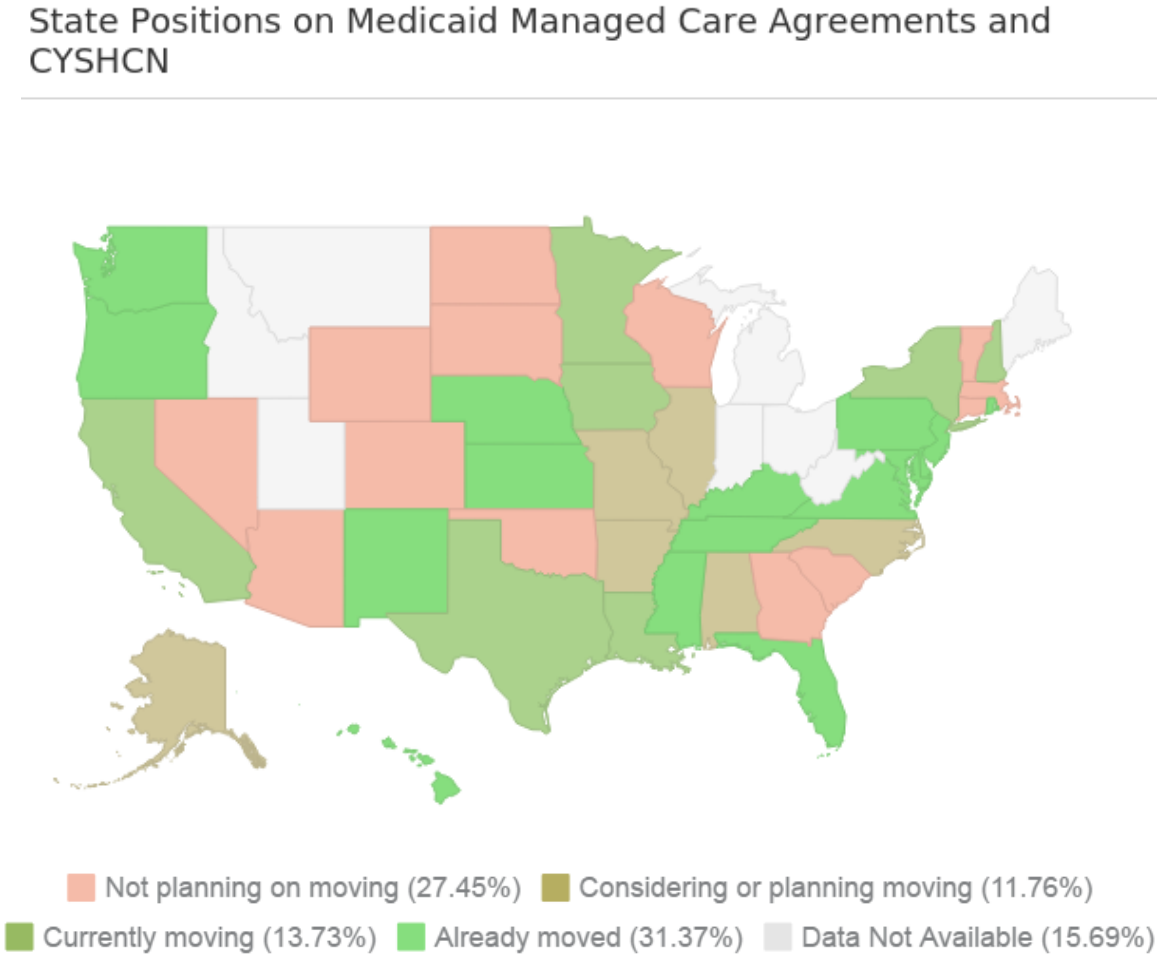
IV. Financing of Care

State CYSHCN agencies' partnerships with Medicaid, CHIP, and state insurance agencies are essential to their involvement in health care reform and financing efforts. In many states, there is opportunity to strengthen CYSHCN involvement; only 16 states reported that CYSHCN staff participates in regular interagency or group meetings related to the ACA or state-driven health reform efforts, and seven were unsure. Moreover, only 12 states reported that their Title V program had an updated Memorandum of Understanding with Medicaid that specified areas of coordination related to the ACA's implementation for MCH and CYSHCN populations. Eight states were unsure whether an updated MOU existed.

Managed care programs have been instituted in many states to contain costs, coordinate care, and monitor the quality of care for children enrolled in Medicaid. Because of their complex needs, however, CYSHCN may be exempt from managed care requirements or may be enrolled in separate systems of care. Sixteen states reported that CYSHCN are now enrolled in Medicaid managed care arrangements; seven are currently moving CYSHCN into Medicaid managed care plans; five are considering moving CYSHCN into managed care; one is planning to do so; and 14 (including the District of Columbia) have no plans to move CYSHCN into managed care.

Eighteen states that have enrolled CYSHCN in Medicaid managed care or are planning to do so reported on their CYSHCN programs' role in this transition. Of these, 6 reported that the Title V CYSHCN program is very involved and working closely with Medicaid and managed care organizations to plan and implement this transition; all of these were states in which CYSHCN are already enrolled in managed care or are currently in the process of being enrolled. Seven states reported that the Title V program is an active partner in the planning and implementation process but is not involved in every aspect of this transition; these were evenly divided across states that have already enrolled CYSHCN in managed care so, are currently doing so, or are planning to do so in the future. The remaining 5 states reported that the Title V CYSHCN program is not involved in this process.

State Innovation Model (SIM) grants from the Centers for Medicare and Medicaid Services are another effort to transform the health care system by implementing multi-payer health care financing and service delivery models to improve health system performance, increase quality, and decrease costs. Twenty-three states reported that their state was awarded a SIM Grant, 10 reported that their state did not receive a grant, and 11 were unsure. Of the 23 that reported that they did receive a SIM grant, 14 reported that their CYSHCN was slightly involved with the grant program, four were moderately involved, one was extremely involved, and four were not at all involved.



V. Emerging Issues

The 2014 National Standards for Systems of Care for CYSHCN, developed under the leadership of AMCHP with support from the Lucile Packard Foundation for Children's Health, provide a structure and framework for CYSHCN agencies' guidance to Medicaid, CHIP, and third party payors and providers as they develop, implement and oversee systems of care for CYSHCN. Title V CYSHCN programs are aware that the Standards can be an essential tool as health system transformation continues in the states. Respondents were asked about their use of the Standards in four contexts and asked to rate their agreement with each statement on a scale of one (strongly disagree) to five (strongly agree). Overall, 34 respondents agreed or strongly agreed that their states had written elements of the Standards in their Title V Block Grant Application (mean=4.17), 35 had shared the Standards with key partners (mean=4.17), 21 had used the Standards as a framework to convene stakeholders (mean=3.59), and 18 had written elements of the Standards into contracts with providers in their states (mean=3.38).

The survey also showed additional opportunity for Title V CYSHCN programs to take a leadership role in policy, advocacy, and financing systems for CYSHCN. Some of the areas in which respondents rated their leadership on the lower end of the scale included reimbursement and financing systems, garnering support for their programs within state government and the private sector, data capacity, financial capacity, and cultural competency.

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

Clearly, state CYSHCN programs face a range of challenges, both internal and external, as the transformation of the health care system continues. It will be essential that these programs develop their capacity to contribute meaningfully to the challenges of financing and overseeing the quality of care for CYSHCN, in the forms of close partnership with public and private payers; leadership in data analysis, financing, and advocacy; and involvement in development of the medical home and other clinical programs. CYSHCN programs will need to continue to develop partnerships beyond the state health and Medicaid agencies, develop skills in financing, and become more closely involved in health systems transformation in their states.

VI. Next Steps

The CYSHCN profile survey reveals a wealth of information on CYSHCN programs across the U.S. While the profile provides a broad picture of current state CYSHCN programs, it does not describe trends in programs over time or provide recommendations on how state CYSHCN programs should be structured or implemented. The data does provide insight into CYSHCN program structure, strengths, partnerships, roles in the overall system of care, financing of care and emerging issues.

The data will be further analyzed to develop resources to assist states in identifying areas to address changes in implementing CYSHCN programs. The profile results and further analysis allow states and territories to compare and improve CYSHCN systems of care and foster cross-state connections and spread of promising practices and strategies. The data will also be used to inform technical assistance opportunities to develop the capacity of CYSHCN programs. Further assessments of this kind would allow for examination of trends and changes in CYSHCN programs over time.

Acknowledgement:

AMCHP extends its sincere thanks and appreciation to the Lucile Packard Foundation for Children's Health (LPFCH) for its funding of this project and report. Its contents are solely the responsibility of the author and do not necessarily represent the official views of LPFCH.

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References:

[1] Association of Maternal & Child Health Programs. Sustaining and Diversifying Family Engagement in Title V MCH and CYSHCN Programs. Washington, DC: 2016. Available from: http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx.

[2] National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from http://www.childhealthdata.org.

[3] Data was gathered from Form 5b of the Title V Maternal and Child Health Services Block Grant, which asks programs to report on "Total Recipient Count of Individuals Served by Title V." Available from: https://mchb.tvisdata.hrsa.gov/.

[4] McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics.* 1998; 102(1):137–140.

[5]Maternal and Child Health Bureau, Health Resource and Services Administration. Children with Special Health Care Needs (Webpage). Available from: https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs.

[6] Association of Maternal & Child Health Programs.
Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs: A White Paper from the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project. Washington, DC: 2014. Available from: http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20White%20Paper%20FINAL.pdf

[7] Association of Maternal & Child Health Programs. Standards for Systems of Care for Children and Youth with Special Health Care Needs. Washington, DC: 2014. Available from: http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20Charts%20FINAL.pdf

[8] Health Resources and Services Administration, Maternal and Child Health Bureau. Title V Maternal and Child Health Services Block Grant Program (Webpage). Available from:https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program.

[9] Kogan M, Dykton C, Hirai AH, et al. A New Performance Measurement System for Maternal and Child Health in the United States. *Maternal and Child Health Journal.* May 2015:19(5);945-957. Available from: https://link.springer.com/article/10.1007/s10995-015-1739-5/fulltext.html.

[10] *Levels of Collaboration Survey developed from*: Frey BB, Lohmeier JH, Lee SW, Tollefson N. Measuring Collaboration Among Grant Partners. *American Journal of Evaluation*. 2006; 27(3): 383-392.