

# Family Engagement in State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) Programs

## A Compilation of Survey Results



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## Acknowledgements

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AMCHP would like to offer a special thanks to Family Voices and its staff for the hard work on the Families in Program and Policy (FiPPs) survey conducted in 2001 and 2002. That ground-laying project was a tremendous asset while compiling the information included in this publication.

AMCHP would also like to express deep gratitude to Julie Preskitt, MSOT, MPH, PhD, assistant professor, University of Alabama at Birmingham School of Public Health, for her work on facilitating the survey design and analyzing data, and to Marjory Ruderman for her technical writing assistance.

### About 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 members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community-based family health professionals, as well as families themselves.

### About the Foundation

The Lucile Packard Foundation for Children’s Health works in alignment with Lucile Packard Children’s Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children’s health, and to increase the quality and accessibility of children’s health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation is a public charity, founded in 1997.

# Family Engagement in State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) Programs: Results from a Survey

## *Executive Summary*

### What is Family Engagement?

In the recently revised Title V Maternal and Child Health Services Block Grant Guidance to states, the U.S. Maternal and Child Health Bureau defines family/consumer partnership as “the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level.”<sup>1</sup>

From late 2014 through early 2015, the Association of Maternal & Child Health Programs (AMCHP) conducted a nationwide survey about family engagement in Title V maternal and child health and special health care needs programs. This executive summary provides key findings from the survey. For more specific information, please consult the seven companion reports, which present the findings in more detail.

### What is Title V?

For more than 80 years, state and territorial maternal and child health programs have worked to improve the health and well-being of women, children and families. For state Title V programs, efforts to engage families generally began in the late 1980's and early 1990's with initiatives in the Title V Children and Youth with Special Health Care Needs (CYSHCN) program. These efforts increased markedly with the addition of provisions in the 1989 Omnibus Budget Reconciliation Act (OBRA) mandating that programs for children with special health care needs assume leadership in the development of family-centered, community-based, coordinated systems of care. The development of a CYSHCN performance measure in 2003 (and the Title V Maternal and Child Health Block Grant requirement to complete Form 13) provided further incentives for both Title V MCH and Title V CYSHCN programs to involve families in a comprehensive manner.<sup>2</sup>

<sup>1</sup> Title V Maternal and Child Health Services Block Grant to States Program: Guidance and forms for the Title V application/annual report. U.S. Department of Health and Human Services, Health Resources and Services Administration, 2015, 33.

<sup>2</sup> Ibid.

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### AMCHP's Interest in Family Engagement

#### Why Survey Now?

Two key motivators for assessing the current state of family participation in Title V programs were the length of time from the last comprehensive assessment and recent changes related to family engagement in the Block Grant Transformation. The last comprehensive family engagement survey of state MCH and CYSHCN directors was conducted in 2002 by Family Voices.

The Families in Program and Policy (FiPPs) reports by Family Voices highlighted results from interviews with state Title V CYSHCN and MCH directors on program activities with families and family groups. Where possible, the 2014 AMCHP survey attempted to collect information similar to the FiPPs interviews, which built on studies conducted by the National Parent Resource Center in 1992.

The revised Block Grant Guidance and requirements create new opportunities for engaging families and consumers as essential partners. Requirements for documenting family/consumer participation are threaded throughout the Block Grant application, including a specific section that asks states to describe their efforts to sustain and diversify family/consumer partnerships.

This expanded requirement for Title V programs to document family participation across the Title V program is a significant change. Previously, states were required only to document family participation in the CYSHCN programs via Form 13: Characteristics Documenting Family Participation in CSHCN Programs.

Furthermore, new National Performance Measures #11 (the percent of children with and without special health care needs having a medical home) and #12 (the percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care) reflect an interest in documenting access to medical home and transition services – for all children and youth, not just CYSHCN.

*"In [my state] and perhaps many other states, the strength of family engagement really lies within the CYSHCN program." MCH Director*

**Who we surveyed and what we learned:** AMCHP sent survey invitations to directors of MCH and CYSHCN programs in all 59 states and jurisdictions. Overall, 71 percent of potential respondents completed surveys: 68 percent of MCH directors (40) and 75 percent of CYSHCN directors (44). The response rate varied across the 10 Health Resources and Services Administration (HRSA) regions, but at least one survey of each type (MCH and CYSHCN) was submitted from every region.

#### Overall Findings:

- Title V programs embrace a broad definition of family, ranging from program participant to both immediate and extended family (the family unit as defined by the participant) as well as youth/young adults as appropriate.
- The majority of MCH and CYSHCN programs that responded to the survey report encouraging or seeking out input from families (97 percent of MCH programs and 100 percent of CYSHCN respondents).
- CYSHCN programs lead state efforts. Both MCH and CYSHCN directors report higher levels of family engagement in CYSHCN programs than in any other MCH program area (child health, maternal, women and adolescent health, and perinatal health).
- Seasoned MCH and CYSHCN directors embrace family engagement: The higher response rates for those with longer tenure (76 percent of MCH respondents and 83 percent of CYSHCN respondents have been in their positions four or more years) may indicate the need to provide continuous guidance and training on family engagement.

**Deeper Dive:** The survey provided a wealth of data grouped along in six key areas:

- [Creating a Culture of Family Engagement](#)
- [Levels of Family Engagement](#)
- [Roles of Family Staff or Consultants](#)
- [Family Members Employed as Staff](#)
- [Sustaining and Diversifying Family Engagement](#)
- [Evaluating Family Engagement](#)

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### Creating a Culture of Family Engagement

An organizational culture that prioritizes family engagement is vital to sustain and improve mechanisms for family engagement and partnership over the long term and across program areas.

Internally: More than three-fourths of programs (76 percent) report providing staff development and training to teach staff members about family engagement in their orientation of new employees. During the performance appraisal process, only 24 percent of CYSHCN programs report incorporating family engagement roles and responsibilities and only 6 percent of MCH programs do so. Likewise, a small percentage of CYSHCN programs (12 percent) and MCH programs (36 percent) report that they are not doing this at all.

Responses to an open-ended question about strategies for promoting an expectation or institutional culture of family engagement suggest that programs are instituting a broad range of strategies, including 1) creating an intentional process/planning structure for improving family engagement and 2) employing a family leader on staff – and leveraging that person’s expertise across programs to model and promote family engagement for other agencies/partners.

Externally: Contracts represent a key opportunity to operationalize family engagement and leverage the expertise of family organizations. Most Title V programs (56 percent of MCH and 73 percent of CYSHCN) have formal agreements (contracts, grants, or memoranda of understanding/agreement) with state or regional family-focused organizations.

### Levels of Engagement

Both MCH and CYSHCN programs report higher levels of family engagement in CYSHCN program areas than in MCH program areas such as child health, maternal, women and adolescent health and perinatal health. This is similar to what Family Voices observed in the FiPPs interviews from 2002, where both MCH and CYSHCN programs described the “CYSHCN programs as touchstones for family participation.”<sup>3</sup>

Both MCH and CYSHCN programs rank transition to adulthood/adult health care as the top program seeking family engagement, followed closely by care coordination and medical home.

### Roles of Family Staff or Consultants within Title V MCH and CYSHCN Programs

Similar to results from the 2002 FiPPs survey, a higher percentage of CYSHCN programs than MCH programs reported employing a family member as staff; likewise, CYSHCN programs are more likely to report employing nurse consultants and outreach specialists. Similarly, CYSHCN programs are more likely than MCH programs to report providing a state salary for family members employed as staff. As with the 2002 survey results, MCH programs also continue to report more family involvement in roles and activities that represent less breadth and depth of engagement, which may indicate the need to provide greater technical assistance and sustenance to programs for engaging families in a deep and meaningful way.

### Family Engagement in the Title V MCH Block Grant

While a small number of MCH program respondents (five) reported no family participation in the Title V Block Grant process in their states, for the most part both MCH and CYSHCN programs report family participation in some capacity, ranging from reviewing and providing feedback on the Block Grant report/application to writing sections of the Block Grant. Likewise, although a small number of respondents from both MCH and CYSHCN programs report that families do not participate in the Title V MCH needs assessment process, by and large both MCH (81 percent) and CYSHCN (88 percent) programs report family participation in the Title V MCH needs assessment process/activities, ranging from participating in surveys, focus groups and/or structured interviews to serving on the program’s internal needs assessment leadership team.

### Family Members Employed as Staff

Most Title V programs employ family members, either directly or through a contract with another

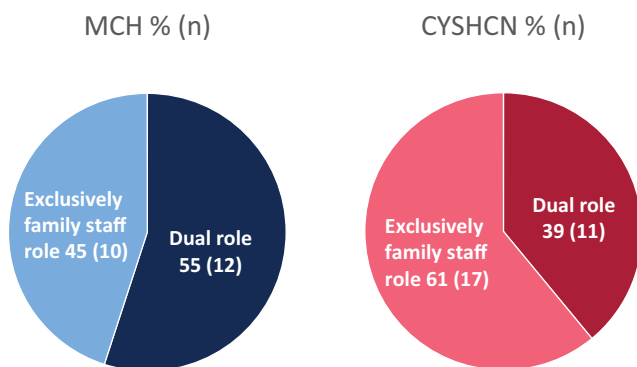
<sup>3</sup>Families in Program and Policy MCH Report. Interviews on Family Participation with State Title V Maternal and Child Health Programs. Retrieved from [http://www.familyvoices.org/admin/miscdocs/files/Fipps\\_MCH\\_Final-1.pdf](http://www.familyvoices.org/admin/miscdocs/files/Fipps_MCH_Final-1.pdf)

## Executive Summary

agency. The practice is more common among CYSHCN programs, with 82 percent of CYSHCN respondents reporting that family members are employed as staff compared with 55 percent of MCH respondents. Offering part-time employment can be an important vehicle to attract parents as employees; both MCH and CYSHCN programs report employing relatively high percentages of part-time staff (76 percent and 67 percent, respectively). What is not known from the data is whether these staff are part-time by choice or because full-time employment is not available.

No clear trends are evident for salary amounts, although not all respondents reported specific salary amounts. For hourly workers, the most common wage range is \$16-20 per hour. States do report efforts to sustain the employment and professional development of staff members in a variety of ways, with opportunities offered by AMCHP (Family Scholars, Family Delegate Program) mentioned frequently.

### Role of Family Staff Members in Program



NOTE: Percentages based on 22 MCH responses and 28 CYSHCN responses to this question.

### Sustaining and Diversifying Family Engagement in Title V Programs

State Title V Programs are required to seek input from families as part of their Block Grant process and ideally they incorporate processes for sustaining and diversifying family engagement in all areas of program assessment, development and assurance. CYSHCN programs continue to solicit input more frequently than MCH programs, but both use a variety of mechanisms to recruit and involve families.

The most common vehicles for family input in CYSHCN programs are partnerships with family organizations, while MCH programs

report utilizing representatives on advisory groups/taskforces. A high percentage of both MCH and CYSHCN programs report seeking input from families using surveys/satisfaction surveys. CYSHCN programs are more likely to report using family representatives as external consultants to seek the family perspective.

When families are asked to rate their agreement with the statement, “My program is successful in its efforts to seek input from special or

*People will show up for an issue that is important to them; you have to know who to call for different purposes.*

diverse populations,” both MCH and CYSHCN programs report average success (indicating a role for greater sustenance and technical assistance here). Using a scale from 1 (strongly disagree) to 5 (strongly agree), the average score for both MCH and CYSHCN program respondents was 3.5. This corresponds with responses from both types of programs, which reported difficulty recruiting culturally diverse families and difficulty recruiting representation across geographic areas or from remote areas as key barriers or challenges. These responses highlight the need for technical assistance in this area.

Some of the key ways that Title V programs recruit families include asking family state consultants and/or other program staff to identify families and invite them to participate, and working with partners such as providers, parent groups and community-based organizations to assist with identifying families. One innovative approach mentioned was to use participant lists from family leadership trainings and other advocacy trainings to recruit families.

When asked how they are institutionalizing family engagement in their programs, both MCH and CYSHCN programs report providing on-going staff development and training as a key strategy, as well as including information related to this strategy in new staff orientation. Disconcertingly, a large percentage of MCH programs responding (36 percent) report that they do not have efforts to teach new and existing staff members about family engagement. This is potentially an area for technical assistance, as formalization of organizational goals and definitions of family engagement can result in both increased engagement and sustainability of family involvement in Title V programs.

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### Evaluation

While both MCH and CYSHCN programs recognize the benefits of family engagement, only a small percentage of programs report having a comprehensive approach to evaluation with standardized indicators of family engagement across programs within the agency (one MCH and four CYSHCN programs). A large percentage of programs report having no evaluation methods at this time (11 MCH and six CYSHCN programs). A key challenge to sustainability is evaluating family engagement efforts. When asked about changes they would like to make to their family engagement efforts over the next year, both MCH and CYSHCN programs reported a high interest in increasing their evaluation capacity related to their family engagement. Furthermore, changes to the Title V Block Grant call for an increased focus on evidence-informed and evidence-based practices. Current evaluation efforts related to family engagement indicate a need for stronger evaluation methodology to strengthen the quality of the evidence base in the family engagement field.

### Ongoing challenges

One of the barriers most cited by both MCH and CYSHCN programs related to engaging families is difficulty recruiting culturally diverse families. Furthermore, MCH programs report difficulty recruiting families interested in more general MCH issues beyond CYSHCN or condition-specific committees. MCH programs also are more likely to report a lack of resources or methods to pay family participants for time and expenses as a barrier. CYSHCN programs cite family time constraints and difficulty recruiting representation across geographic areas or from remote areas as top barriers to their efforts to engage families in their work.

### Training & Technical Assistance Needs

CYSHCN and MCH programs report a need for strategies to recruit and engage culturally diverse, under-represented and under-served families, and a desire to learn more about how changes related to family engagement in the Title V Block Grant transformation may impact their programs. Both MCH and CYSHCN programs are looking for successful models to engage families in general MCH issues (non-CYSHCN programs). Likewise, both types of programs report a high need for training and technical assistance around methods to evaluate the extent, impact and effectiveness of family engagement.

### What does this mean?

Family engagement is an essential part of state Title V MCH and CYSHCN programs. Yet the clearest message to emerge from the survey results is that state Title V programs continue to struggle with the nuts and bolts of practically and meaningfully employing, compensating and engaging families. While CYSHCN programs lead these efforts in state Title V programs, there is clearly a great need to identify and promote models and practices that work, as well as roles for the many partners who support the work of Title V programs, including AMCHP, the Maternal and Child Health Bureau (MCHB), and other MCHB-funded technical assistance centers. Key areas of focus for technical assistance include orienting staff to family engagement, engaging families from diverse backgrounds and evaluating family engagement. The transformation of the Title V Block Grant offers opportunities to promote family engagement throughout the programs, but states will need support and assistance to strengthen family participation in all aspects of program and policy.

### Next steps

The survey is intended as a starting point for further work to drive innovation in practices and policies that support meaningful family engagement in Title V programs. As a follow-up to the survey, AMCHP plans to engage in further discussion with Title V programs around these issues; take a deeper dive into the data and responses; and explore the idea of surveying families and comparing perspectives.

# Family Engagement in Title V MCH and CYSHCN Programs: Survey Overview

From late 2014 to early 2015, the Association of Maternal & Child Health Programs (AMCHP) conducted a survey about family engagement policies and practices in Title V maternal and child health (MCH) and children and youth with special health care needs (CYSHCN) programs, with funding from the Lucile Packard Foundation for Children's Health and the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services. The survey findings provide a snapshot from the perspective of Title V programs of current strategies to support meaningful family engagement, effective and innovative practices, and areas of need for improvement and technical assistance.

In addition to this overview of the survey, a series of companion reports details specific areas of interest from the survey results:

- [Creating a Culture of Family Engagement](#)
- [Levels of Family Engagement](#)
- [Roles of Family Staff or Consultants](#)
- [Family Members Employed as Staff](#)
- [Sustaining and Diversifying Family Engagement](#)
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## Survey Development

Historically, MCH and CYSHCN programs have differed in their approaches to and requirements for family engagement. Given those differences, as well as their varying program areas and populations served, two parallel versions of the survey were created: one for MCH directors and one for CYSHCN directors. The

survey questions drew from a 2002 survey of family participation in Title V programs by Family Voices<sup>1</sup>; from two focus groups conducted in 2014 by AMCHP with directors and staff of Title V MCH and CYSHCN programs and with family leaders; and from a review of new family engagement requirements in the Title V MCH Services Block Grant Application/Annual Report guidance. An advisory group composed of state and national Title V and family advocacy leaders, including members of the AMCHP Family and Youth Leadership Committee, guided the development of the survey by an academic consultant with expertise in survey design and analysis. (See end of this section for work group membership.) Four former state MCH and CYSHCN directors and senior program staff completed a pilot test of the survey in October 2014, and their feedback informed the final revision.

## Survey Response

Directors of MCH and CYSHCN programs in all 59 states and jurisdictions received invitations to complete the survey online via SurveyMonkey in November 2014. AMCHP sent two follow-up requests directly to non-respondents and promoted the survey in two editions of Member Briefs (an AMCHP newsletter) and on regional calls in November and December 2014.

Overall, 71 percent of the directors completed surveys: 68 percent of MCH directors (40) and 75 percent of CYSHCN directors (44).<sup>2</sup> The response rates varied across the 10 HRSA regions, but at least one survey of each type (MCH and CYSHCN) was submitted from every region.

<sup>1</sup>Families in Program and Policy: FIPPS CSHCN Report ([https://org2.salsalabs.com/o/6739/images/Fipps\\_CSHCN\\_Final-1.pdf](https://org2.salsalabs.com/o/6739/images/Fipps_CSHCN_Final-1.pdf)) and FIPPS MCH Report ([http://www.family-voices.org/admin/miscdocs/files/Fipps\\_MCH\\_Final.pdf](http://www.family-voices.org/admin/miscdocs/files/Fipps_MCH_Final.pdf)).

<sup>2</sup>Total n for individual survey items varies due to skip patterns and nonresponses.



## Response Rates by Region

	MCH % (n)	CYSHCN % (n)
All states and jurisdictions	68 (40)	75 (44)
HRSA Region 1: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont	83 (5)	100 (6)
HRSA Region 2: New Jersey, New York	50 (1)	50 (1)
HRSA Region 3: Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia	40 (2)	80 (4)
HRSA Region 4: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee	87 (7)	75 (6)
HRSA Region 5: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin	83 (5)	100 (6)
HRSA Region 6: Arkansas, Louisiana, New Mexico, Oklahoma, Texas	80 (4)	100 (5)
HRSA Region 7: Iowa, Kansas, Missouri, Nebraska	100 (4)	100 (4)
HRSA Region 8: Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming	67 (4)	83 (5)
HRSA Region 9: Arizona, California, Hawaii, Nevada	75 (3)	50 (2)
HRSA Region 10: Alaska, Idaho, Oregon, Washington	50 (2)	100 (4)
Territories: American Samoa, Federated States of Micronesia, Guam, Marshall Islands, Northern Mariana Islands, Palau, Puerto Rico, Virgin Islands	33 (3)	11 (1)

### Respondent Characteristics

Most surveys were completed by the original recipients: MCH directors (84 percent of MCH survey respondents) and CYSHCN directors (88 percent of CYSHCN survey respondents). The remaining 12 percent of CYSHCN respondents and 16 percent of MCH respondents were program staff designees.



More than half (62 percent) of MCH directors in the responding states have been in their position fewer than four years, compared with 38 percent of CYSHCN directors. Directors of responding programs tended to have had a long tenure with the Title V agency (at any level/position), with 50 percent of MCH directors and 47 percent of CYSHCN directors having been with the organization more than 10 years.

### Organizational Structure

For the majority of programs (84 percent of responding MCH programs and 73 percent of responding CYSHCN programs), decision-making authority related to financing, service delivery and other policy is centralized at the state level. Other organizational structures include decentralized authority and combination models.

Most of the responding CYSHCN programs (62 percent) are housed organizationally with the Title V MCH program. The others are located in the same agency but in a separate division (19 percent) or in a different agency or organization than the MCH program (19 percent).

### Definitions of Family

Title V programs define “family” broadly, with most including not just immediate family but also extended family and youth. Some respondents indicated that the program defers to the client’s own definition of family or that the program has no formal definition.

## Programmatic Definitions of “Family”

	MCH % (n)	CYSHCN % (n)
Program participant	82 (31)	n/a*
Immediate family (spouse, parents, stepparents, guardians, siblings, etc.)	92 (35)**	100 (42)
Extended family (grandparents, aunts, uncles, cousins, etc.)	74 (28)	74 (31)
Includes youth as appropriate	79 (30)	86 (36)

NOTE: 38 MCH respondents answered this question; 42 CYSHCN respondents answered this question.

\*“Program participant” was not included as a response option in the CYSHCN survey.

\*\*Only three respondents did not select “immediate family,” and two of these indicated that their programs have no formal definition.

## Use of Survey Results

Recent changes to the Title V MCH Services Block Grant strengthened the focus on family engagement and created more stringent requirements for engaging families in program planning and assessment. These changes apply for both MCH and CYSHCN program areas. This survey provides important information about the range, depth, and perceived effectiveness of strategies to engage families in Title V program planning and improvement activities prior to implementation of the new Block Grant guidance.

While the response rate was high and sufficient to identify trends, innovation practices, and areas of need, the results might not represent the family engagement practices of programs that did not respond. Most importantly, the responses reflect the perspectives of Title V programs. In addition, the views of families and family advocate organizations, which were not captured by this survey, are vital to create a complete picture of family engagement in Title V programs. This survey focused only on Title V program responses and is a starting point for further work by AMCHP with its state and national partners to drive practice and policy change to support meaningful family engagement in Title V programs.

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