

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

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 (MCH) and children and youth with special health care needs (CYSHCN) programs. Out of 59 states and territories with Title V funding, 68 percent of MCH programs (40) and 75 percent of CYSHCN programs (44) responded.<sup>1</sup> The survey results reflect the perspectives of responding Title V programs about the range, depth, and effectiveness of strategies to engage families in program planning and improvement activities. A full picture of family engagement in Title V programs requires the views of families and family organizations as well. The survey is intended as 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. This report discusses various roles, and activities within these roles, of families who are in paid positions as staff or consultants.

## Family Members as Staff or Consultants to Title V Programs

High percentages of both MCH and CYSHCN programs work with families, as staff employed directly by the Title V agency, as contract employees (i.e., another agency employs the family member through a contract with the Title V program), and/or as external consultants to the program.

On the MCH side, 55 percent of respondents (22) report employing family members directly as staff or contract employees, while an even greater percentage of CYSHCN programs (82 percent, or 31 respondents) report employing family members. Each type of program reports using families as external consultants at high rates (more than 80 percent for both).



<sup>1</sup>Total n for individual survey items varies due to skip patterns and nonresponses.

## Roles for Family Members Working with Title V Programs

The survey presented an extensive list of potential family roles, strategies, and activities, and respondents indicated which ones are assigned to families working with the Title V program. Responses are aggregated to include engagement by family members hired directly as staff members, as contract employees or as external consultants.

### Roles for Family Engagement Highlighted in the Title V MCH Block Grant Guidance

The new Title V MCH Services Block Grant (Title V MCH Block Grant) guidance requires more comprehensive discussion and assessment of family engagement in Title V programs. The guidance specifies several types of activities in which states must demonstrate efforts to support family engagement:

- Advisory Committees
- Strategic and Program Planning
- Quality Improvement
- Workforce Development
- Block Grant Development and Review
- Materials Development
- Advocacy

Among these activities highlighted in the Title V MCH Block Grant guidance, serving on project-, issue-, or condition-specific advisory and work groups garnered the highest percentages of both MCH and CYSHCN respondents indicating that family members fulfill this role in their programs, followed by serving on general program advisory groups. Advocating about MCH issues, funding, and legislation received the lowest percentages, though still roughly half of both MCH and CYSHCN respondents indicated these strategies do play a role for family engagement.

### Roles for Family Engagement Highlighted in Title V Block Grant Guidance

|                                    | Role, Strategy or Activity  | MCH % (n)* | CYSHCN % (n)** |
|------------------------------------|---|------------|----------------|
| Advisory Committees                | Serve on specific project, issue or condition advisory groups, committees, taskforces and work groups                                 | 97 (30)    | 93 (37)        |
|                                    | Serve on general program advisory groups and committees   | 90 (28)    | 88 (35)        |
| Block Grant Development and Review | Participate in Title V Block Grant and needs assessment activities  | 81 (25)    | 88 (35)        |
| Materials Development              | Develop, review, or provide feedback on publications and education/ outreach materials  | 52 (16)    | 80 (32)        |
| Strategic and Program Planning     | Participate in program development, planning and goal setting   | 61 (19)    | 78 (31)        |
|                                    | Provide input on program activities   | 87 (27)    | 90 (36)        |
|                                    | Review and/or develop program policies and procedures   | 48 (15)    | 55 (22)        |
| Workforce Development              | Participate in program staff trainings as planners, speakers or co-presenters   | 58 (18)    | 75 (30)        |
|                                    | Supervise other family members or staff (e.g., recruiting, serving on interview teams, orienting, training, mentoring and evaluating) | 26 (8)     | 55 (22)        |
| Quality Improvement                | Participate in program quality improvement initiatives  | 55 (17)    | 60 (24)        |
|                                    | Participate in program evaluation and monitoring  | 42 (13)    | 60 (24)        |
| Advocacy                           | Provide education and information about MCH issues to policymakers and legislators  | 55 (17)    | 60 (24)        |
|                                    | Advocate about MCH issues, funding and legislation to policymakers and legislators  | 48 (15)    | 50 (20)        |

\*Percentages based on 31 MCH respondents who reported having family engagement with their program.

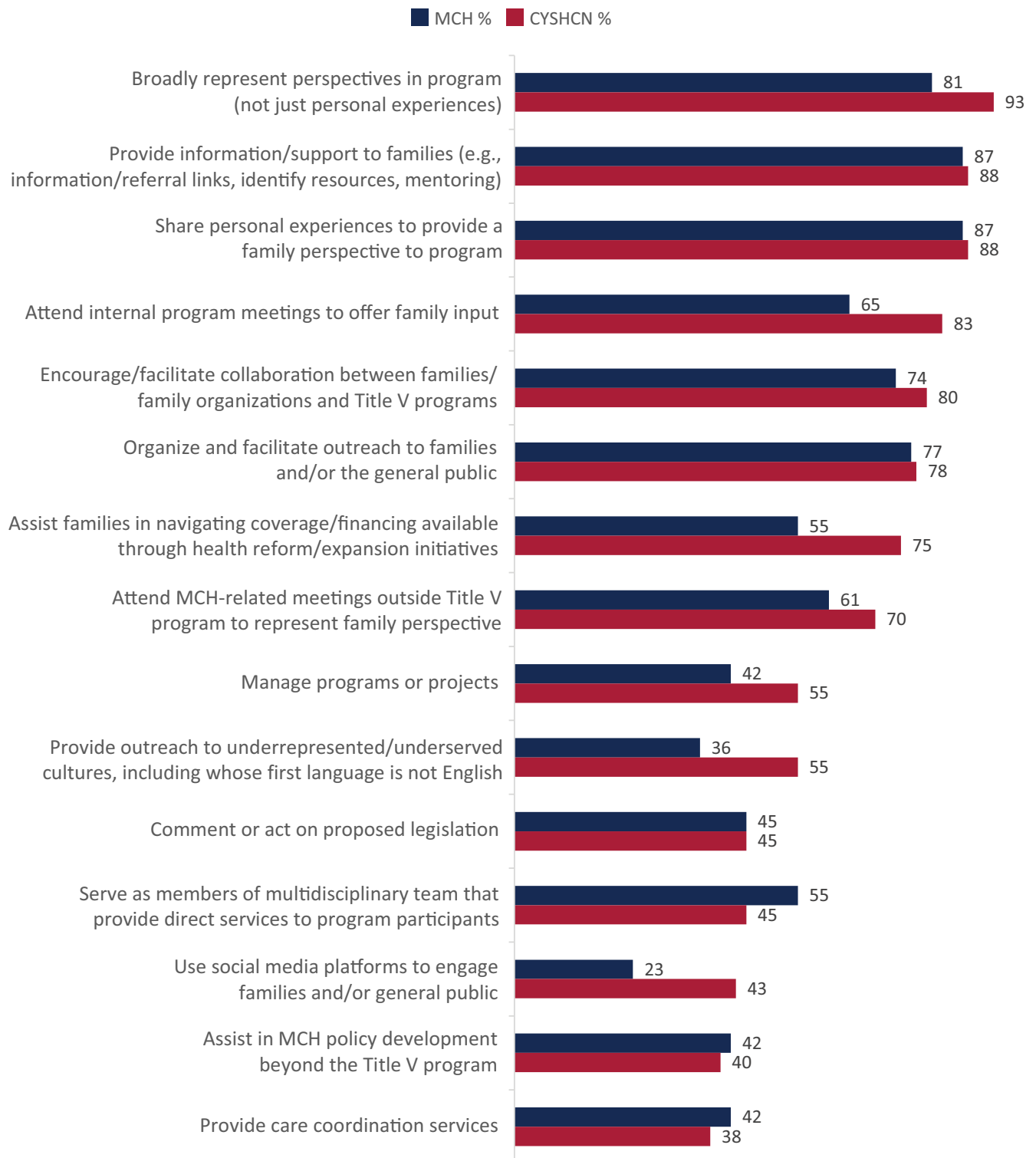
\*\* Percentages based on 40 CYSHCN respondents who reported having family engagement with their program.

## Other Roles for Family Engagement

Among other roles, strategies, and activities (not specifically highlighted in the Title V Block Grant guidance), the ones most frequently identified by both MCH and CYSHCN programs as having family engagement include:

- Sharing personal experiences to provide a family perspective to the program
- More broadly representing family perspectives in the program (not just personal experiences)
- Providing information or support to families (e.g. information and referral, parent-to-parent information or links, resources identification, mentoring)

## Other Roles For Families (Total n = 31 MCH and 40 CYSHCN Respondents)



## Depth of Engagement: Family Roles Along a Continuum

Family engagement occurs along a continuum representing increasing levels of engagement. The terminology used to define these levels and the types of roles or activities they include were categorized with input from the survey advisory group. For the purposes of this survey, the program activities in which families might play a role were categorized as:

- 1) Basic input into Title V programs
- 2) Partnership with Title V programs
- 3) Service provision to other families and/or within the Title V program
- 4) Policy-level leadership

Within each level, scores for each program were calculated based on the numbers of roles/activities for which the respondent reported family engagement. Mean scores differ by program type (MCH or CYSHCN), but none of the differences are significant based on comparison of standard deviations.

| Roles/Activities by Level of Engagement  | Range of Possible Scores | MCH* Mean (SD)      | CYSHCN** Mean (SD)   |
|--|--------------------------|---------------------|----------------------|
| <b>Input</b> <ul style="list-style-type: none"> <li>Share personal experiences to provide a family perspective to program</li> <li>Serve on specific project/issue/condition advisory groups, taskforces, work groups</li> <li>Provide input on program activities</li> </ul>  | 0-3                      | 2.71<br>(2.49-2.93) | 2.70<br>(2.43-2.97)  |
| <b>Partnership</b> <ul style="list-style-type: none"> <li>More broadly represent family perspectives in program (not just personal experiences)</li> <li>Serve on general program advisory groups and committees</li> <li>Attend internal program meetings to offer family input</li> <li>Develop/review/provide feedback on publications and education/outreach materials</li> <li>Participate in program staff trainings as planners, speakers and/or co-presenters</li> <li>Organize and facilitate outreach to families and/or the general public</li> <li>Provide outreach to diverse and under-represented or under-served cultures, including those whose first language is not English</li> <li>Use social media platforms to engage families and/or the general public</li> <li>Review and/or develop program policies and procedures</li> <li>Participate in Title V MCH Block Grant and needs assessment activities</li> <li>Participate in program development, planning and goal setting</li> <li>Participate in program evaluation and monitoring</li> <li>Participate in program quality improvement initiatives</li> </ul> | 0-13                     | 7.68<br>(6.34-9.02) | 9.32<br>(8.13-10.52) |
| <b>Service Provision</b> <ul style="list-style-type: none"> <li>Provide care coordination services</li> <li>Serve on multidisciplinary teams that provide direct services to program participants</li> <li>Manage programs or projects</li> <li>Supervise other family members or staff (e.g., recruiting, serving on interview teams, orienting, training, mentoring and evaluating)</li> <li>Provide information or support to families (e.g., information and referral, parent-to-parent information or links, resource identification, mentoring)</li> <li>Assist families in navigating and understanding coverage and financing opportunities available through health reform and expansion initiatives</li> </ul>   | 0-6                      | 3.06<br>(2.45-3.68) | 3.55<br>(3.00-4.10)  |
| <b>Policy-Level Leadership</b> <ul style="list-style-type: none"> <li>Attend MCH-related meetings outside Title V program to represent family perspective</li> <li>Assist in MCH policy development beyond the Title V program</li> <li>Comment or act on proposed legislation</li> <li>Provide education and information about MCH issues to policymakers and legislators</li> <li>Advocate about MCH issues, funding and legislation to policymakers and legislators</li> <li>Encourage/facilitate collaboration between families/family organizations and Title V programs (e.g., coalition building, increasing communication and collaboration)</li> </ul>  | 0-6                      | 3.26<br>(2.47-4.05) | 3.45<br>(2.77-4.13)  |

\* Percentages based on 31 MCH respondents who reported having family engagement with their program.

\*\* Percentages based on 40 CYSHCN respondents who reported having family engagement with their program.

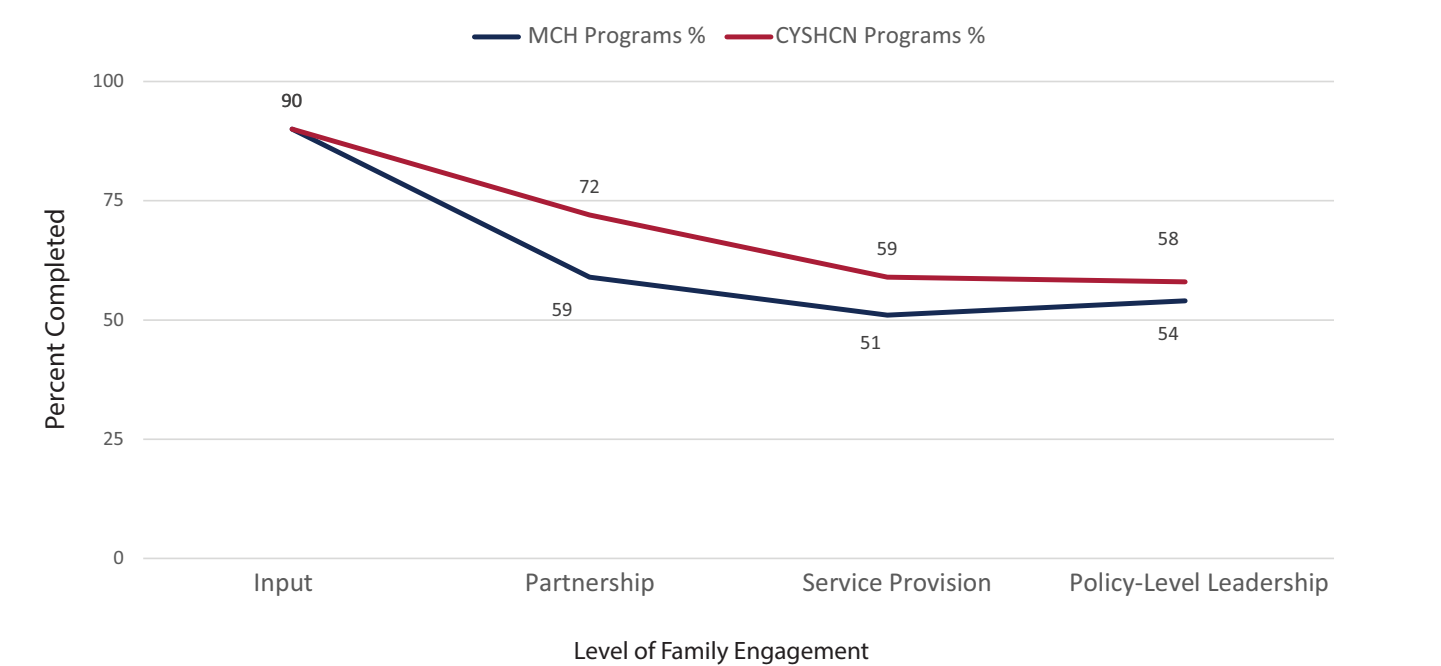


The “percent completed” was calculated for each level by dividing the mean score (average number of roles/activities with family engagement) by the total score possible (total number of roles/activities included in the level). For both MCH and CYSHCN programs, the percent completed decreases as the degree of family engagement increases. In other words, programs report greater family involvement in roles and activities that represent less breadth and depth of engagement. As the degree of engagement represented increases, family involvement declines. Calculations are based

on the 31 MCH respondents and 40 CYSHCN respondents who reported having family engagement with their programs.

| Level of Engagement     | Percent Completed |        |
|-------------------------|-------------------|--------|
|                         | MCH               | CYSHCN |
| Input                   | 90                | 90     |
| Partnership             | 59                | 72     |
| Service Provision       | 51                | 59     |
| Policy-Level Leadership | 54                | 58     |

Percent Completed (based on total possible score) by Level of Family Engagement



## Family Engagement in the Title V MCH Block Grant and Needs Assessment

There are many ways families may participate in the preparation and review of states' annual Title V MCH Block Grant application/report and five-year needs assessment. The survey presented a list of potential roles for families in these two federally required processes, and respondents selected all that currently apply in their states.

## Title V MCH Block Grant Activities

The ranked order of activities by frequency of family engagement is the same for both MCH and CYSHCN programs. Most respondents (but not all) report that families review and provide feedback on the Title V MCH Block Grant report/application. Less than one-third of both MCH and CYSHCN respondents report that families write sections of the Block Grant report/application. For other Block Grant-related activities, MCH and CYSHCN responses differ by 10 to 12 percentage points, with CYSHCN respondents consistently reporting more family participation.

### Family Participation in Title V MCH Block Grant Activities

| Activity  | MCH <sup>1</sup> |    | CYSHCN <sup>2</sup> |    |
|---|------------------|----|---------------------|----|
|   | %                | n  | %                   | n  |
| Review and provide feedback on Block Grant report/application           | 65               | 24 | 75                  | 33 |
| Participate in Block Grant review with federal officials                | 49               | 18 | 61                  | 27 |
| Contribute data for Block Grant report/application                      | 38               | 14 | 50                  | 22 |
| Assist in activities/measurement of National/State Performance Measures | 38               | 14 | 48                  | 21 |
| Write sections of Block Grant report/application                        | 27               | 10 | 32                  | 14 |

<sup>1</sup>Percentages based on 37 MCH responses to this question.

<sup>2</sup>Percentages based on 44 CYSHCN responses to this question.

## Title V MCH Block Grant Five-Year Needs Assessment Activities

As with activities related to the Block Grant, the order of most frequently reported needs assessment-related activities with family participation is the same for MCH and CYSHCN programs. Most but not all MCH and CYSHCN respondents report that families participate

in surveys, focus groups, and/or structured interviews as part of the needs assessment process. In more than half of MCH and CYSHCN programs, families assist in identifying state MCH/CYSHCN priorities. The smallest percentage of respondents report that families serve on the internal (within the Title V agency) needs assessment leadership team.

### Family Participation in Five-Year Needs Assessment Activities

| Activity  | MCH <sup>1</sup> |    | CYSHCN <sup>2</sup> |    |
|---|------------------|----|---------------------|----|
|   | %                | n  | %                   | n  |
| Participate in surveys, focus groups, and/or structured interviews                        | 84               | 31 | 80                  | 35 |
| Assist in prioritizing and/or selecting state MCH/CYSHCN priorities                       | 57               | 21 | 61                  | 27 |
| Contribute data on family needs collected through a family led organization               | 43               | 16 | 55                  | 24 |
| Serve on a broad needs assessment advisory committee (may include external organizations) | 43               | 16 | 52                  | 23 |
| Assist in the development of program performance/outcome measures and action plans        | 43               | 16 | 50                  | 22 |
| Serve on the program's internal (within agency) needs assessment leadership team          | 35               | 13 | 32                  | 14 |

<sup>1</sup>Percentages based on 37 MCH responses to this question.

<sup>2</sup>Percentages based on 44 CYSHCN responses to this question.



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