AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

July 2016

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 ChildHealth (MCH) and Children with Special Health Care Needs (CYSHCN) Programs: Results from a Survey
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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."[1]

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.[2]

[1] 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.

[2] Ibid.

Executive Summary

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.

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

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.

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."[3]

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

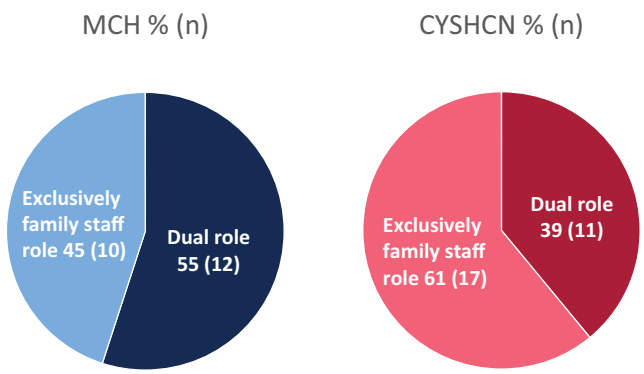
Most Title V programs employ family members, either directly or through a contract with another

[3] 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

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.

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

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

Executive Summary

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
- Evaluating Family Engagement

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[1]; 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).[2] 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.

[1]Families in Program and Policy: FIPPS CSHCN Report (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).
[2]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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Creating a Culture of Family Engagement in 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.[1] 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.

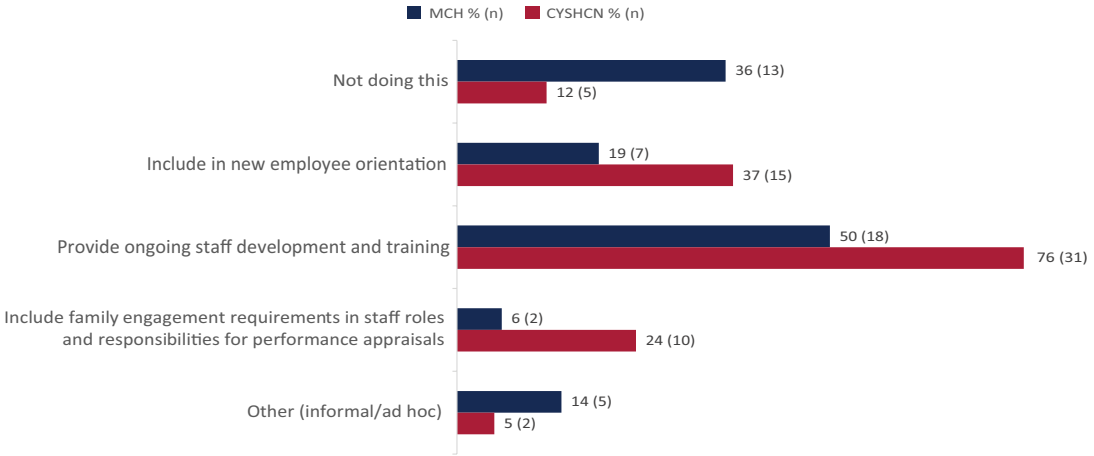
An organizational culture that prioritizes family engagement is vital to sustain and improve mechanisms for family engagement and partnership over the long term and across program areas. Some of the tangible ways that Title V programs institutionalize a culture of family engagement include providing professional development opportunities for staff members, incorporating family engagement into contracts and funding mechanisms, and supporting family advocate organizations. This report outlines information from the survey related to creating a culture of family engagement and highlights efforts to institutionalize this culture.

Developing Staff Knowledge and Skills

Most respondents report that their programs provide ongoing staff development and training to teach staff members about family engagement (50 percent of MCH programs and 76 percent of CYSHCN programs). Fewer than half include topics related to family engagement in orientation of new employees (19 percent of MCH programs, 37 percent of CYSHCN programs). Very few programs report that they incorporate family engagement roles and responsibilities in performance appraisal processes. More than one-third of MCH programs report having no mechanisms for teaching staff members about family engagement. A small percentage of respondents indicate that their programs informally or periodically teach staff about family engagement through activities such as parent-led presentations at staff meetings, informal discussions and guidance from supervisors and interactions with family members on staff.

[1]Total *n* for individual survey items varies due to skip patterns and nonresponses.

How Does Your Program Teach New and Existing Staff Members about Family Engagement?



NOTE: 36 MCH respondents answered this question; 41 CYSHCN respondents answered this question.

Family Engagement Requirements in Contracts and Grants

Just under half of MCH respondents and 61 percent of CYSHCN respondents report that their programs at least sometimes include requirements for family engagement in service provision contracts, subcontracts or grants to other agencies. The number of MCH programs including family engagement requirements in contracts might be smaller than these responses suggest; asked to provide specific examples, some MCH program respondents provided examples of family engagement requirements in CYSHCN program funding mechanisms.

Require Family Engagement in Service Provision Contracts	MCH % (n)	CYSHCN % (n)
Yes	14 (5)	39 (16)
Sometimes	30 (11)	22 (9)
No	38 (14)	34 (14)
Not sure	19 (7)	5 (2)

NOTE: 37 MCH answered this question; 41 CYSHCN respondents answered this question.

Most of the examples given by respondents make general reference to Title V-funded projects that are required to have some type of family engagement (e.g., case management, transition, newborn screening, Healthy Start, home visiting, family resource centers). Respondents also noted a number of specific contract/grant requirements and accountability mechanisms:

- Requiring family representatives as paid staff and/or as participants on advisory groups
- Requiring specific staff members to attend at least one family event annually
- Requiring client satisfaction surveys/assessment
- Including information on coordination with family support organizations in grant applications
- Including family engagement as a program standard for local public health agency accreditation

Supporting Family Organizations

Most Title V programs (56 percent of MCH and 73 percent of CYSHCN) have formal agreements (contract, grant or memoranda of understanding/agreement) with state or regional family focused organizations. The majority of programs also support family organizations through participation in or sponsorship of conferences. In-kind services provided by Title V programs to family organizations include staff support for boards and commissions, staff participation on committees, dissemination of information through Title V program communication channels, co-location of offices, and provision of office goods (e.g., supplies, equipment, postage, furniture).

Support Type	MCH % (n)	CYSHCN % (n)
Formal contracts, grants, MOU/MOA	56 (20)	73 (32)
Participation in/sponsorship of conferences	58 (21)	59 (26)
In-kind services	17 (6)	48 (21)
Informal agreements	25 (9)	43 (19)
Training/technical assistance	39 (14)	41 (18)
Office space/meeting space	25 (9)	39 (17)
Costs of printing materials	22 (8)	36 (16)
Direct funds	31 (11)	34 (15)
Translation/interpreter services	14 (5)	20 (9)
Clerical support (e.g., for newsletter, mailings)	14 (5)	16 (7)
None	14 (5)	0 (0)

NOTE: 36 MCH respondents answered this question; 44 CYSHCN respondents answered this question.

Promoting an Expectation of Family Engagement

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 at all levels of program operation. Common strategies are highlighted below, along with specific examples of their use.

General Strategies	Examples
Creating an intentional process/planning structure for improving family engagement	– Survey program managers for input on family engagement across multiple areas (e.g., advisory committees, planning, quality improvement and measurement, workforce development, Block Grant, advocacy, cultural competency) – Survey district staff for input on family engagement – Created Think Tank Team to use the person-centered planning tool to develop an organizational strategic plan to enhance family engagement, which will be incorporated into five-year needs assessment plan – Provide small grants to local health departments to support family engagement
Employing a family leader on staff – and leveraging that person's expertise across programs	– Employ family leaders/parent coordinators – Encourage family leader on staff to participate in cross-office work, serve on committees and ad hoc groups – Provide opportunities for family staff/consultants to present during bureau and regional program meetings
Training program staff and partners	– Train all staff across programs/offices, as well as lead staff at contracted partners – Involve family partners in training new staff about the value of family leadership and support – Discuss the importance of family input and engagement in new staff orientation
Including family representatives in our own policy and planning activities	– Offer matches between programs and parents wanting engagement – Family members attend coordinator meetings in case management system – Always ask whether or not we have a family voice/perspective available – Advisory bodies comprised of or including family representatives at multiple levels (program, agency, state) – Include family representation/input at all levels of policy and program development and other planning, assessment and improvement activities
Modeling and promoting family engagement for other agencies/partners	– Ask if the family/consumer voice also will be at the table when invited to other meetings, offer assistance finding someone, and ask if the family representative(s) will be paid – Consistently model engagement for program staff and relevant partners (e.g., include families at meetings and in trainings and grant reviews, pay for family consultation time) – CYSHCN staff facilitate collaborative efforts with other state agencies and community organizations to promote family engagement in all aspects of program/policy decision making and evaluation – Maternal, Infant and Early Childhood Home Visiting continuous quality improvement process encourages parent representation at Level 2/Local Level
Incorporating family engagement into contracts and requirements of service providers	– Include requirements/language about family engagement in contracts and RFPs – Require clinics to include families on advisory boards and in all staff meetings – State statute requires Healthy Start Coalitions to include consumers, including at least two who are low-income or Medicaid-eligible
Leveraging the expertise of family organizations	– Designate a family organization to serve as lead agency in state implementation grants – Contract with outside organizations to ensure family engagement
Demonstrating the value placed on family perspective	– Require staff to attend Parent Consultant Advisory Committee meetings and activities – MCH director meets quarterly with a large Family Case Management Group that brings their clients
Engaging families in needs assessment and Block Grant review	– Integrate families into needs assessment process (e.g., survey, focus groups) – Conduct special outreach to families for input on the annual report/application and the needs assessment – Include families in regional/MCHB site visit

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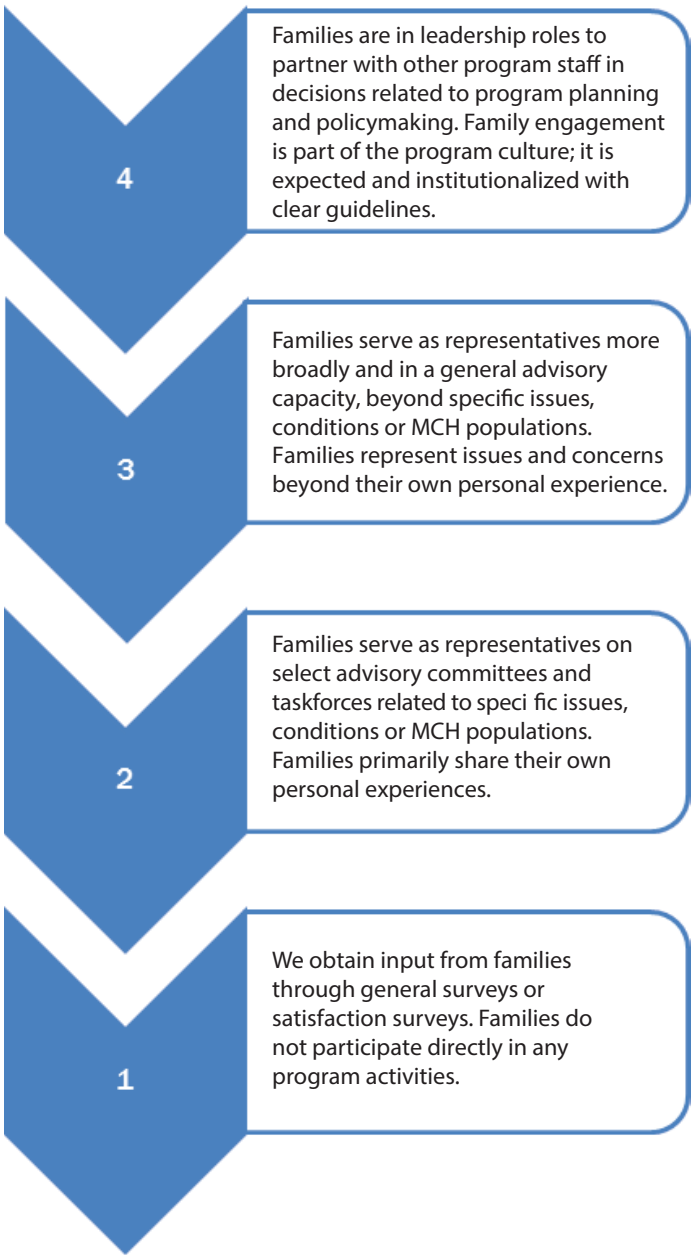
Levels of Family Engagement in Title V MCH and CYSHCN Programs

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.[1] 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 looks at the degree to which families are engaged in various program areas and issues across four successive levels of engagement.

Overall Levels of Family Engagement

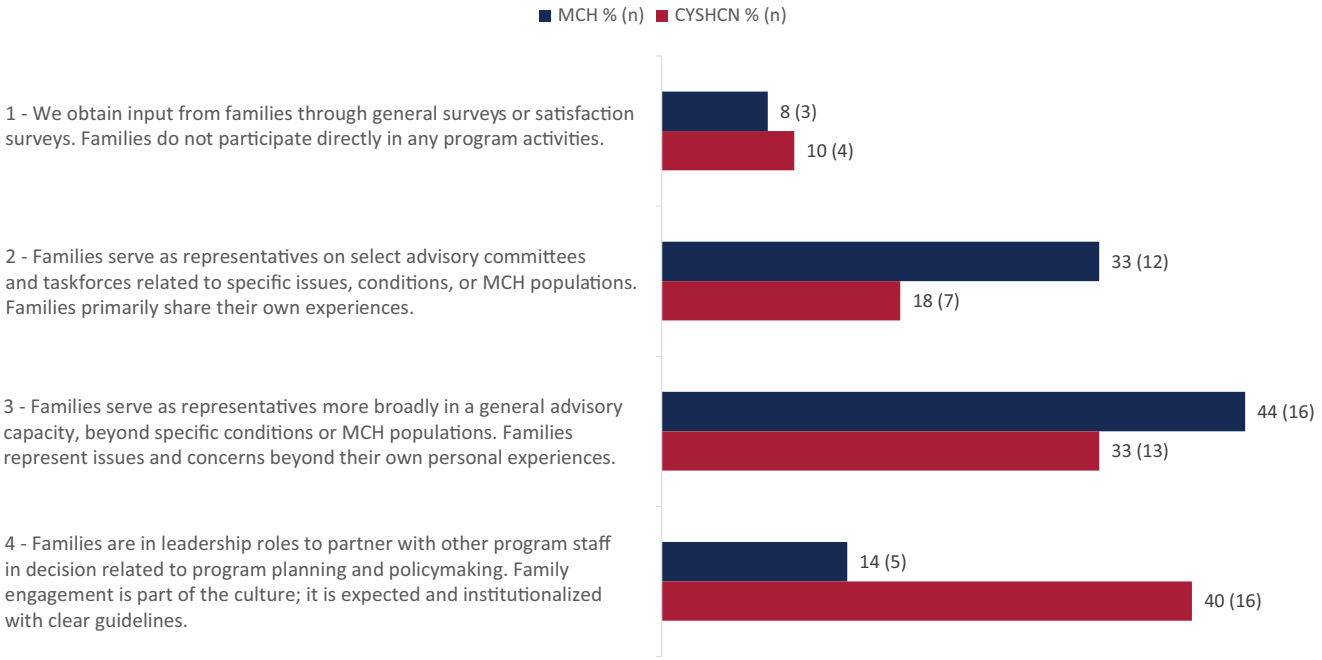
Respondents rated their overall program level of family engagement on a scale from one to four, with higher numbers indicating higher levels of engagement.

Compared with MCH programs, CYSHCN programs scored themselves higher, indicating higher levels of family engagement. More than 70 percent of CYSHCN respondents rated their program level of family engagement as a 3 or 4, compared with 58 percent of MCH respondents. On average, CYSHCN respondents scored 3.02 (95 percent CI=2.70-3.34) and MCH respondents scored 2.36 (95 percent CI=2.08-2.64). The difference between these mean scores is statistically significant (t=-3.12;p=0.0025;t-test).



[1]Total n for individual survey items varies due to skip patterns and nonresponses.

Overall Levels of Family Engagement



NOTE: 36 MCH respondents answered this question; 40 CYSHCN respondents answered this question.

Levels of Family Engagement by Program Area

Respondents also rated their program level of family engagement in major population-focused program areas, using a scale from 0 (none) to 5 (high). Both MCH and CYSHCN programs report the highest levels of family engagement (as indicated by mean scores) for children and youth with special health care needs, followed by child health.

Program Area	MCH Mean (95% CI)	CYSHCN Mean (95% CI)
Perinatal Health	1.94 (1.44-2.44)	2.25 (1.69-2.81)
Maternal, Women and Adolescent Health	2.19 (1.66-2.72)	2.36 (1.79-2.93)
Child Health	2.88 (2.41-3.36)	3.11 (2.67-3.55)
Children and Youth with Special Health Care Needs	4.21 (3.88-4.54)	4.17 (3.82-4.53)

NOTE: 35 MCH respondents answered this question; “don’t know” was set to missing.
40 CYSHCN respondents answered this question; “don’t know” was set to missing.

Levels of Family Engagement by Issue

Using the same five-point scale (from 0=none to 5=high), respondents rated their program level of family engagement in selected issue areas. For both MCH and CYSHCN programs, the three issues with the highest mean scores – indicating the highest levels of family engagement – were transition to adulthood/adult health care, care coordination/case management, and medical home. These issues often are considered under the purview of CYSHCN programs, though the new National Performance Measures for the Title V MCH Services Block Grant include percent of children with and without special health care needs who have a medical home and who received services to support transition to adult health care.

Family Engagement by Issue Area

(from highest to lowest level of engagement for each program type)

	MCH mean score 95% CI	CYSHCN mean score 95% CI	
Transition to adulthood/adult health care	3.19 (2.70-3.69)	3.70 (3.31-4.09)	Transition to adulthood/adult health care
Care coordination/case management	3.10 (2.60-3.59)	3.31 (2.76-3.86)	Medical home
Medical home	2.54 (1.93-3.15)	3.27 (2.79-3.75)	Care coordination/case management
Medicaid	2.24 (1.59-2.88)	3.15 (2.59-3.72)	Health care financing/health reform
Oral health	2.19 (1.59-2.80)	3.11 (2.54-3.67)	Medicaid
Nutrition/pysical activity programs	2.15 (1.50-2.79)	2.90 (2.30-3.51)	Emergency preparedness
Obesity/overweight initiatives	2.04 (1.42-2.65)	2.50 (1.84-3.16)	Children's Health Insurance Progam
Emergency preparedness	2.05 (1.07-3.03)	2.37 (1.85-2.90)	Oral health
Children's Health Insurance Progam	2.00 (1.31-2.68)	2.33 (1.80-2.87)	Racial and ethnic disparities
Racial and ethnic disparities	1.81 (1.19-2.44)	2.10 (1.46-2.74)	Smoking/tobacco cessation
Smoking/tobacco cessation	2.00 (1.42-2.58)	2.08 (1.64-2.53)	Nutrition/physical activity programs
Health care financing/health reform	1.52 (0.83-2.21)	2.04 (1.56-2.53)	Obesity/overweight initiatives

NOTE: 35 MCH respondents answered this question; "don't know" was set to missing. 42 CYSHCN respondents answered this question; "don't know" was set to missing.

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.[1] 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).

[1]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

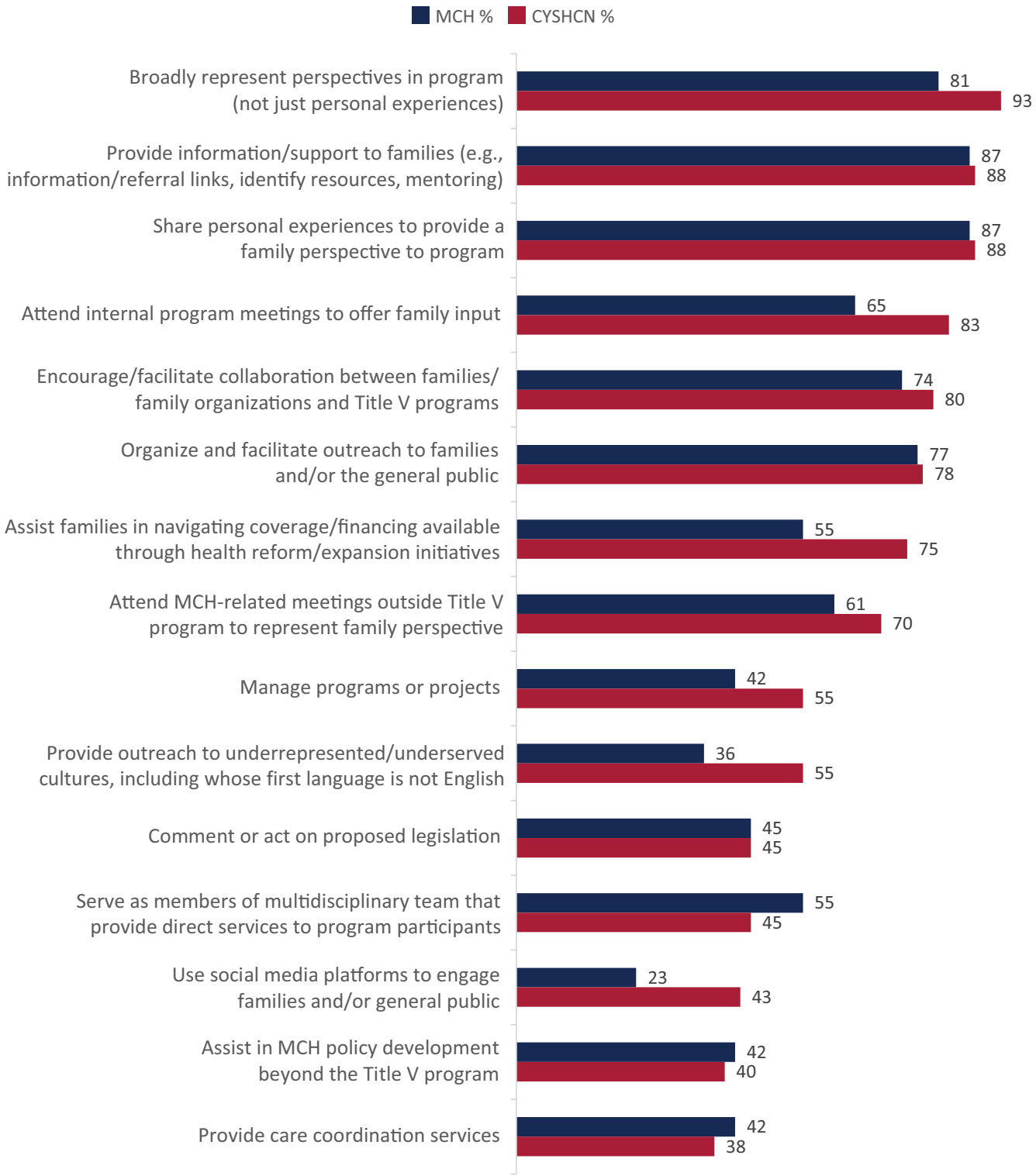
	Role, Strategy or Activity	MCH % (n)*	CYSHCN % (n)**
Advisory Committees	Serve on specific project, issue or condition advisory groups, committees, taskforces and work groups	97 (30)	93 (37)
	Serve on general program advisory groups and committees	90 (28)	88 (35)
Block Grant Development and Review	Participate 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.

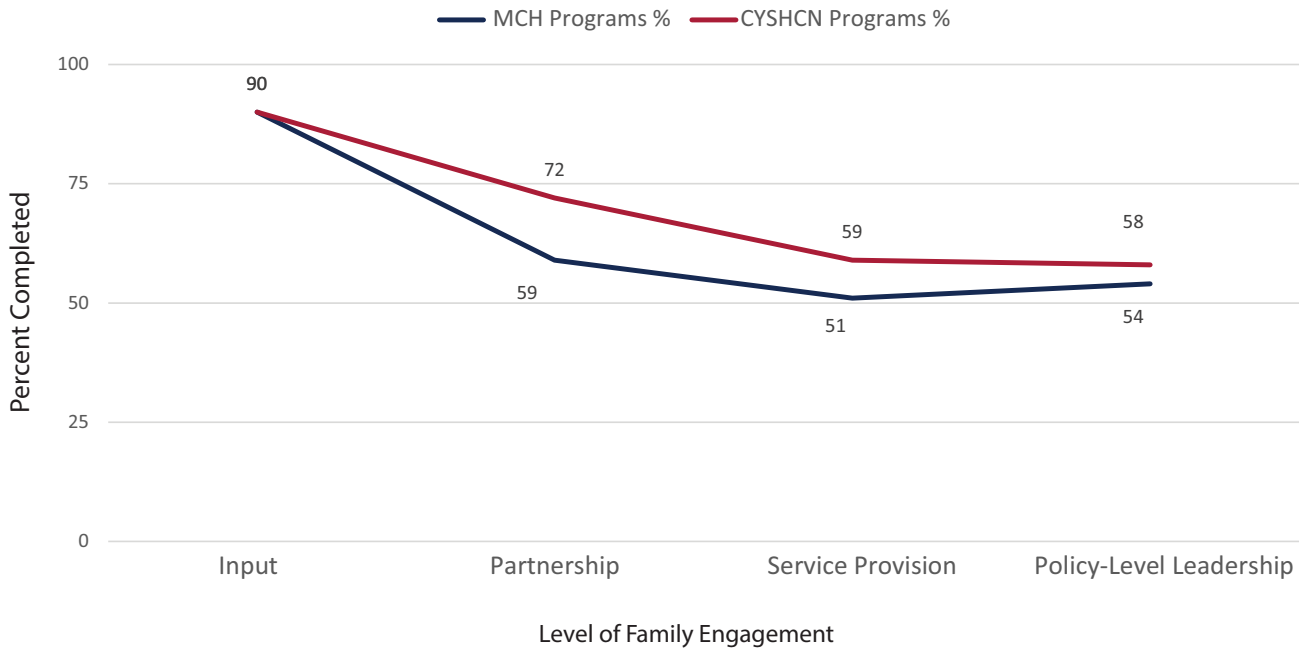
Roles/Activities by Level of Engagement	Range of Possible Scores	MCH* Mean (SD)	CYSHCN** Mean (SD)
Input – Share personal experiences to provide a family perspective to program – Serve on specific project/issue/condition advisory groups, taskforces, work groups – Provide input on program activities	0-3	2.71 (2.49-2.93)	2.70 (2.43-2.97)
Partnership – More broadly represent family perspectives in program (not just personal experiences) – Serve on general program advisory groups and committees – Attend internal program meetings to offer family input – Develop/review/provide feedback on publications and education/outreach materials – Participate in program staff trainings as planners, speakers and/or co-presenters – Organize and facilitate outreach to families and/or the general public – Provide outreach to diverse and under-represented or under-served cultures, including those whose first language is not English – Use social media platforms to engage families and/or the general public – Review and/or develop program policies and procedures – Participate in Title V MCH Block Grant and needs assessment activities – Participate in program development, planning and goal setting – Participate in program evaluation and monitoring – Participate in program quality improvement initiatives	0-13	7.68 (6.34-9.02)	9.32 (8.13-10.52)
Service Provision – Provide care coordination services – Serve on multidisciplinary teams that provide direct services to program participants – Manage programs or projects – Supervise other family members or staff (e.g., recruiting, serving on interview teams, orienting, training, mentoring and evaluating) – Provide information or support to families (e.g., information and referral, parent-to-parent information or links, resource identification, mentoring) – Assist families in navigating and understanding coverage and financing opportunities available through health reform and expansion initiatives	0-6	3.06 (2.45-3.68)	3.55 (3.00-4.10)
Policy-Level Leadership – Attend MCH-related meetings outside Title V program to represent family perspective – Assist in MCH policy development beyond the Title V program – Comment or act on proposed legislation – Provide education and information about MCH issues to policymakers and legislators – Advocate about MCH issues, funding and legislation to policymakers and legislators – Encourage/facilitate collaboration between families/family organizations and Title V programs (e.g., coalition building, increasing communication and collaboration)	0-6	3.26 (2.47-4.05)	3.45 (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[1]		CYSHCN[2]	
	%	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

[1]Percentages based on 37 MCH responses to this question.
[2]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[1]		CYSHCN[2]	
	%	n	%	n
Participate in surveys, focus groups, and/or structured interviews	84	31	80	35
Assist in prioritizing and/or selecting state MCH/CSHCN 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

[1]Percentages based on 37 MCH responses to this question.
[2]Percentages based on 44 CYSHCN responses to this question.

Family Members Employed as Staff in 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.[1] 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 examines the employment and compensation of families who are staff, including their part/full-time status, hourly wages, and salary ranges.

Employment Mechanisms

Most Title V programs employ family members, either directly or through a contract with another 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. Programs employ family members more often through contracts with other organizations than through the Title V agency directly, and most family staff members are employed at the state level.

Role of Family Staff Members

Respondents were asked whether family members employed by their programs either directly or through contracts with other agencies serve exclusively in a dedicated parent/family staff role, or also fill another staff role (e.g., a nurse who is a parent of a child with special health care needs, a program coordinator who

[1]Total n for individual survey items varies due to skip patterns and nonresponses.

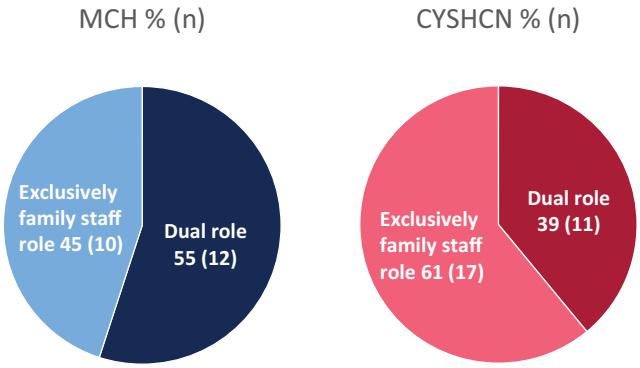
Family Engagement and Position

	MCH % (n)	CYSHCN % (n)
Among all respondents:		
Employ family members as staff (either directly or through contract with another agency)*	55 (21)	82 (36)
Among programs that employ family staff members:		
How Title V programs employ family staff members		
Employed directly by the program	48 (10)	42 (15)
Employed though a contract with another agency	86 (18)	72 (26)
Levels of program where family members are employed		
State	86 (18)	86 (31)
Regional	38 (8)	39 (14)
County/local/city	48 (10)	31 (11)

* Percentages based on 38 MCH responses and 44 CYSHCN responses to this question.

is a recipient of MCH services). A slight majority of CYSHCN respondents report that family staff members serve exclusively in a parent/family role, while a slight majority of MCH respondents report that family staff members serve dual roles.

Role of Family Staff Members in Program



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

Employment Terms

Hours Worked

Family staff members are employed by Title V programs in both full-time and part-time positions. The hours for part-time positions most often are 10 to 20 hours per week, or they vary based on specific contracts, projects, and program areas.

Family Staff Members' Employment Status

Hours Worked	MCH % (n)	CYSHCN % (n)
Full-time (40 hours per week)	52 (11)	72 (26)
Part-time*	76 (16)	67 (24)
Less than 10 hours per week	0	9 (2)
10-20 hours per week	53 (9)	26 (6)
21-30 hours per week	12 (2)	17 (4)
31-39 hours per week	6 (1)	9 (2)
Varies based on contract, program area, or project	29 (5)	39 (9)

*** Percentages based on 21 MCH responses and 36 CYSHCN responses to this question.**

Compensation

In close to half of both MCH and CYSHCN programs, family members on staff are salaried employees, and in roughly two-thirds of programs, family staff members earn an hourly wage. (Programs may employ both salaried and hourly family staff members.) Most programs also offer benefits to family staff members.

Family Staff Members' Compensation

Type of Compensation	MCH % (n)	CYSHCN % (n)
Salary	57 (12)	46 (16)
Hourly wage	67 (14)	69 (25)
Benefits (retirement, sick leave, vacation)	67 (14)	72 (26)

NOTE: Percentages based on 21 MCH responses and 36 CYSHCN responses to this question.

No clear trends are evident for salary amounts. However, not all respondents who reported that family staff members earn a salary also provided the amount. Of the 16 CYSHCN respondents who reported that family staff members earn a salary, 15 provided an amount. Only seven of the 12 MCH respondents who reported that family staff members earn a salary provided an amount.

Among programs that compensate family staff members with an hourly wage, the most common wage is $16 to $20 per hour. Out of 25 CYSHCN respondents reporting that family staff members earn an hourly wage, 20 provided a wage amount. Of 14 MCH respondents reporting that family staff members earn an hourly wage, nine provided an amount.

Salary and Wage Amounts	MCH % (n)*	CYSHCN % (n)*
Salary		
Less than $15,000 per year	0	0
$15,001-$25,000 per year	14 (1)	0
$25,001-$35,000 per year	14 (1)	27 (4)
$35,001-$45,000 per year	14 (1)	20 (3)
$45,001-$55,000 per year	29 (2)	27 (4)
More than $55,000 per year	29 (2)	27 (4)
Hourly wage		
Less than $10 per hour	11 (1)	0
$11-$15 per hour	22 (2)	25 (5)
$16-$20 per hour	44 (4)	45 (9)
$21-$25 per hour	0	25 (5)
More than $25 per hour	22 (2)	5 (1)

*Salary amounts reported by seven of 12 possible MCH respondents and 15 of 16 possible CYSHCN respondents. Hourly wage amounts reported by nine of 14 possible MCH respondents and 20 of 25 possible CYSHCN respondents.

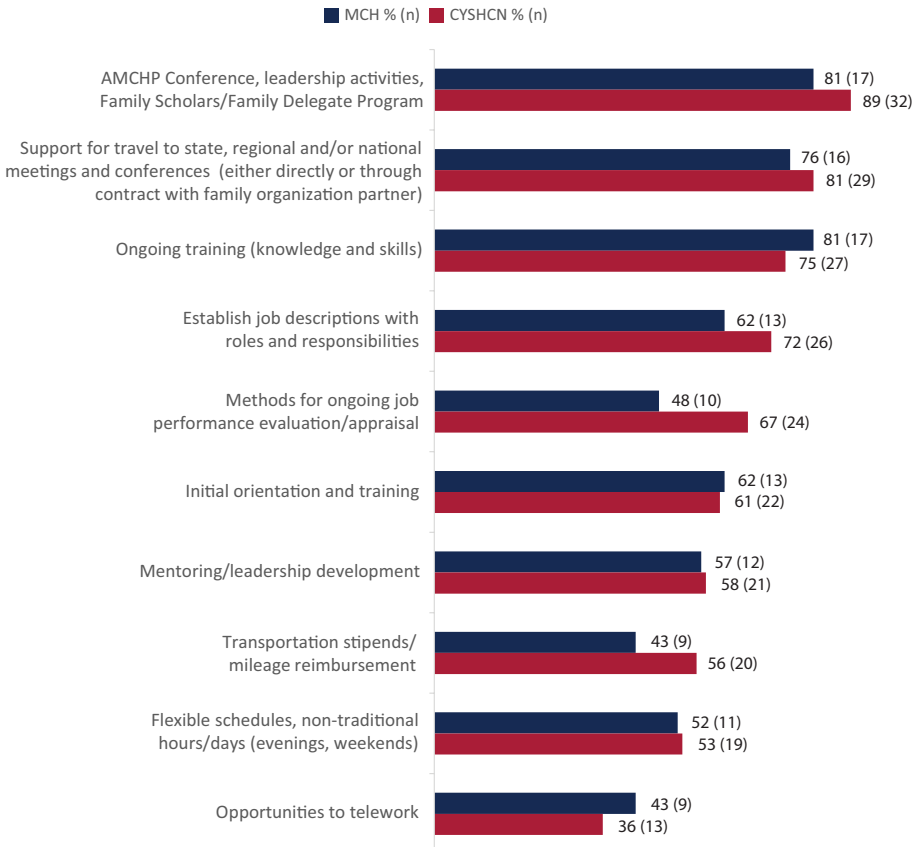
Support for Family Staff Members

Title V programs support the employment and professional development of family staff members in a number of ways. The most common mechanisms for both MCH and CYSHCN programs are opportunities offered by AMCHP, such as attending its Annual Conference and participating in the Family Scholars Program, Family Delegate Program, or other leadership activities. Among MCH programs, an equal number provide family staff members with ongoing training to build knowledge and skills. Support for travel to state, regional, or national meetings is similarly common across programs.

Among MCH programs, 62 percent have established job descriptions with roles and responsibilities for family staff members, but only 48 percent have methods for ongoing job performance evaluation or appraisal. By comparison, 72 percent of CYSHCN respondents report having such job descriptions and 67 percent report having methods for ongoing performance appraisal.

Mechanisms that assist work-life balance, such as flexible schedules or opportunities to telework, are among the less frequently reported supports for family staff members, but still are offered by between one-third and one-half of programs.

Supports for Family Staff Members



NOTE: Percentages based on 21 MCH responses and 36 CYSHCN responses to this question.

Sustaining and Diversifying Family Engagement in 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.[1] 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 describes how often families provide input to MCH and CYSHCN programs, how they are recruited, and ways they are engaged. It also shares the types of support provided to families to make to their engagement successful. The quantitative data in the report are derived from the family engagement survey. Qualitative information, such as examples of specific practices and policies, comes from open-ended survey responses, follow-up discussions with survey respondents, and discussions with Title V program staff and family leaders held during the 2015 AMCHP Annual Meeting.

Seeking Input from Families: Methods, Frequency and Reaching Diverse Populations

Methods for Obtaining Family Input

For both MCH and CYSHCN programs, the most common vehicles for family input are partnerships with family organizations and family representatives serving on advisory groups and surveys (including satisfaction surveys). CYSHCN programs are more likely than MCH programs to employ family members as program staff and to engage family members as external consultants.

Top Methods for Soliciting Family Input

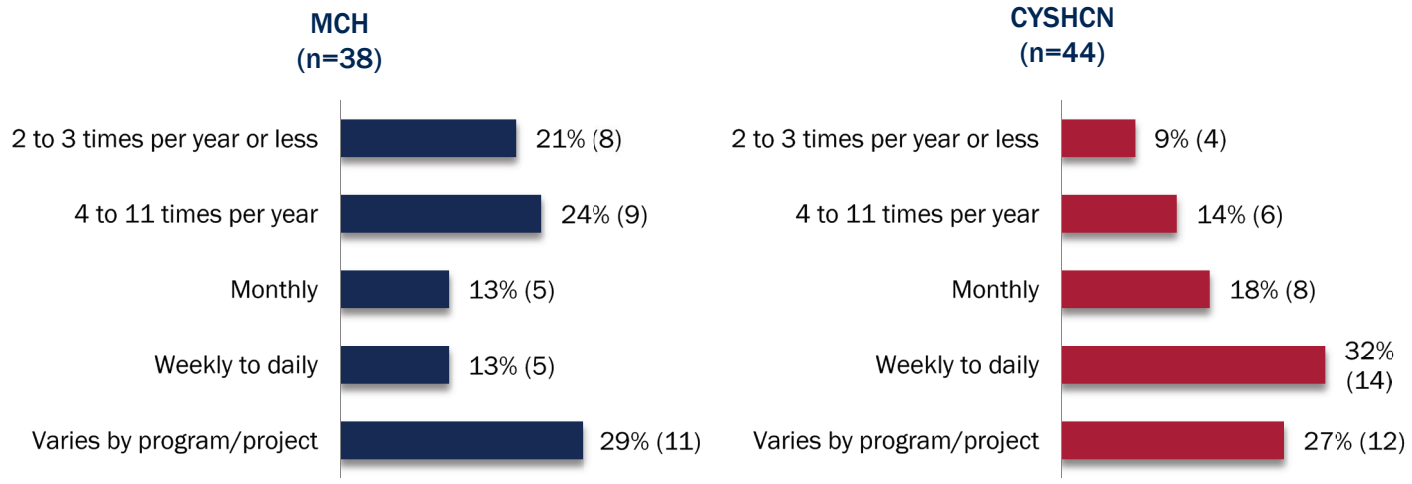
	CYSHCN % (n)	MCH % (n)	
Partnerships with family organizations	98 (43)	84 (32)	Representatives on advisory groups
Representatives on advisory groups	91 (40)	82 (31)	Partnerships with family organizations
Surveys/satisfaction surveys	89 (39)	76 (29)	Surveys/satisfaction surveys
Family representatives as external consultants	75 (33)	66 (25)	Focus groups/structured interviews
Family representatives on staff	66 (29)	66 (25)	Public notices of opportunities for input
Focus groups/structured interviews	66 (29)	55 (21)	Family representatives as external consultants
Public notices of opportunities for input	55 (24)	53 (20)	Methods to provide input through website
Methods to provide input through website	50 (22)	53 (20)	Public hearings with opportunities for input
Public hearings with opportunities for input	48 (21)	45 (17)	Family representatives on staff
Methods to provide input through social media	32 (14)	32 (12)	Methods to provide input through social media

NOTE: 38 MCH respondents answered this question; 44 CYSHCN respondents answered this question.

[1]Total n for individual survey items varies due to skip patterns and nonresponses.

Frequency of Family Input
CYSHCN programs appear to seek family input more frequently than MCH programs, though numbers were too small to determine whether these differences are statistically significant. For more than one-quarter of programs, the frequency varies depending on the program area or project activity.

Frequency of Soliciting Family Input



Obtaining Input from Diverse Populations
Respondents rated their agreement with the statement, "My program is successful in its efforts to seek input from special and/or diverse populations, including those whose first language is not English and those who need alternative/accessible formats for communication," using a scale from 1 (strongly disagree) to 5 (strongly agree). The average score for both MCH and CYSHCN program respondents was 3.5. No respondents from either program selected "strongly disagree."

Engaging Families in Advisory Groups: Recruitment and Participation

Recruiting Family Representatives
Most programs (both MCH and CYSHCN) identify potential family representatives with the help of family staff/consultants, other program staff and family organizations. More than 75 percent of respondents report using each of these sources of referrals to identify potential advisory group participants. A smaller percentage of respondents, but still more than half, report using recommendations from other community-based groups, partner organizations, and health care providers to identify potential family representatives. Respondents rated the success of their efforts to recruit participation of family representatives from diverse populations on a scale from 1 (strongly disagree) to 5 (strongly agree). The average scores for MCH directors and CYSHCN directors were not significantly different.

My Program is Successful in its Efforts to Seek Input from Diverse Populations, Including Those Whose First Language is Not English and Those Who Need Accessible Formats for Communication

Score	Response	MCH % (n)	CYSHCN % (n)
1	Strongly disagree	0	0
2	Disagree	16 (6)	9 (4)
3	Neither	29 (11)	36 (16)
4	Agree	45 (17)	50 (22)
5	Strongly agree	11 (4)	5 (2)
	mean score	3.5	3.5

NOTE: 38 MCH respondents answered this question; 44 CYSHCN respondents answered this question.

My Program is Successful in Including Family Representatives from Diverse Populations, Including Those Whose First Language is Not English and Those Who Need Accessible Formats for Communication

Score	Response	MCH % (n)	CYSHCN % (n)
1	Strongly disagree	3 (1)	3 (1)
2	Disagree	25 (8)	15 (5)
3	Neither	38 (12)	36 (12)
4	Agree	31 (10)	39 (13)
5	Strongly agree	3 (1)	6 (2)
	mean score	3.1	3.3

NOTE: 32 MCH respondents answered this question; 33 CYSHCN respondents answered this question.

State Title V program staff and family leaders report a variety of specific strategies for identifying potential family representatives who reflect the range of families receiving Title V services:

- Connect with families through programs such as Early Intervention, Newborn Screening and specialty clinics
- Obtain a list of children with an Individualized Education Program and related plans, and connect with their families through the schools
- Create a diagnosis-based registry/database
- Build question(s) about interest in participating on advisory committees into application forms and follow-up systems
- Partner with organizations already engaged with communities and populations of interest
- Recruit from different regional areas
- Attend to cultural and racial/ethnic diversity, but also to diversity of children's ages and inclusion of fathers
- Use data to determine which families to engage in specific areas (e.g., infant mortality data might point toward a need to engage more with African American fathers in some regions)
- "Our kids are kids first," said one CYSHCN staff member. Even in CYSHCN programs, family representatives ideally offer insights beyond CYSHCN-specific issues

In addition, some states found that family members are more receptive to participation in targeted activities or for specific purposes. For instance, families in medical home practices might serve on quality improvement committees for a medical home initiative. As one discussion participant noted, "People will show up for an issue that is important to them; you have to know who to call for different purposes."

Extent of Family Participation on Advisory Groups
Respondents were asked to rate the extent to which family consultants are involved as representatives on advisory groups, committees, taskforces and work groups on a scale from 0 (no involvement) to 4 (institutionalized involvement). The mean response from CYSHCN directors (2.6) was higher than that from MCH directors (2.0), a difference that was statistically significant.

A higher percentage of CYSHCN directors (57 percent) than MCH directors (39 percent) reported "extensive" or "institutionalized" engagement, indicating that more than 75 percent of groups include family representatives. The number of family representatives varies from group to group in most MCH and CYSHCN programs.

Sustaining Family Engagement: Compensation, Support and Training

Sustaining meaningful engagement of families starts at recruitment, with clarity about what the program is asking of them. State Title V leaders suggest providing a range of opportunities requiring varying levels of time and commitment; they note that family members who are engaged in smaller ways at first might become more deeply engaged over time. Programs vary widely in the logistical and financial supports they provide for family representative participation, as well as in the training and leadership development opportunities they offer.

Financial Compensation and Other Supports for Family Representatives on Advisory Groups
The most common financial compensation for family representative attendance at advisory group meetings is a transportation stipend or mileage reimbursement. Fewer programs provide a participation stipend/ honorarium or child care stipend. Few respondents specified stipend amounts; typically, the amounts vary based on available funding, time commitment, and travel distance. Some programs pay the established state reimbursement rate for mileage and per diem. Among programs that provide no financial support for family representative participation on advisory groups,

Representation of Families on Advisory Bodies and Working Groups

Score	Response Category	MCH % (n)	CYSHCN % (n)
4	Institutionalized engagement (95-100% of groups include families)	10 (4)	32 (14)
3	Extensive engagement (76-94% of groups include families)	28 (11)	25 (11)
2	Moderate engagement (50-75% of groups include families)	18 (7)	25 (11)
1	Minimal engagement (<50% of groups include families)	33 (13)	11 (5)
0	No engagement at this time	10 (4)	7 (3)
	mean score	2.0	2.6

NOTE: 39 MCH respondents answered this question; 44 CYSHCN respondents answered this question.

the most commonly cited reasons include prohibition on this kind of payment (by agency or governor), funding limitations, and lack of a mechanism for providing compensation.

A majority of programs support the engagement of family representatives on advisory groups by providing alternative ways to participate and by varying meeting locations for convenience. More than one-third of programs provide orientation, ongoing training, and mentorship for family representatives, as well flexible meeting times to facilitate their attendance.

Training for Family Representatives
Respondents were asked about formal and informal training for families involved in program activities, provided either by the program directly or by linking to other resources. The most common opportunity offered by MCH and CYSHCN programs is participation in the AMCHP Annual Conference, Family Scholars Program, and/or Family Delegate Program. A majority of programs provide training on the Title V MCH Services Block Grant and needs assessment processes and meeting preparation (e.g., background, attendees, acronyms). For each topic, higher percentages of CYSHCN respondents than MCH respondents report providing training. However, numbers are too small in some categories to determine the statistical significance of these differences.

Only 27 percent of MCH respondents and 34 percent of CYSHCN respondents indicate that their programs provide training on MCH Leadership Competencies (MCHLC). Given that the new (as of 2015) Title V MCH Services Block Grant Guidance requires states to report the number of family members/ consumers receiving training on MCHLC in their needs assessment summaries, these survey responses suggest room for improvement in this area of training.

Other Supports for Family Representatives on Advisory Groups

Support Type	MCH % (n)	CYSHCN % (n)
Alternative ways to participate	79 (27)	72 (31)
Varying meeting locations for convenience	50 (17)	70 (30)
Initial orientation and training	41 (14)	47 (20)
Flexible meeting and event times	35 (12)	56 (24)
Mentoring (developing leadership skills)	32 (11)	51 (22)
Ongoing training	29 (10)	49 (21)

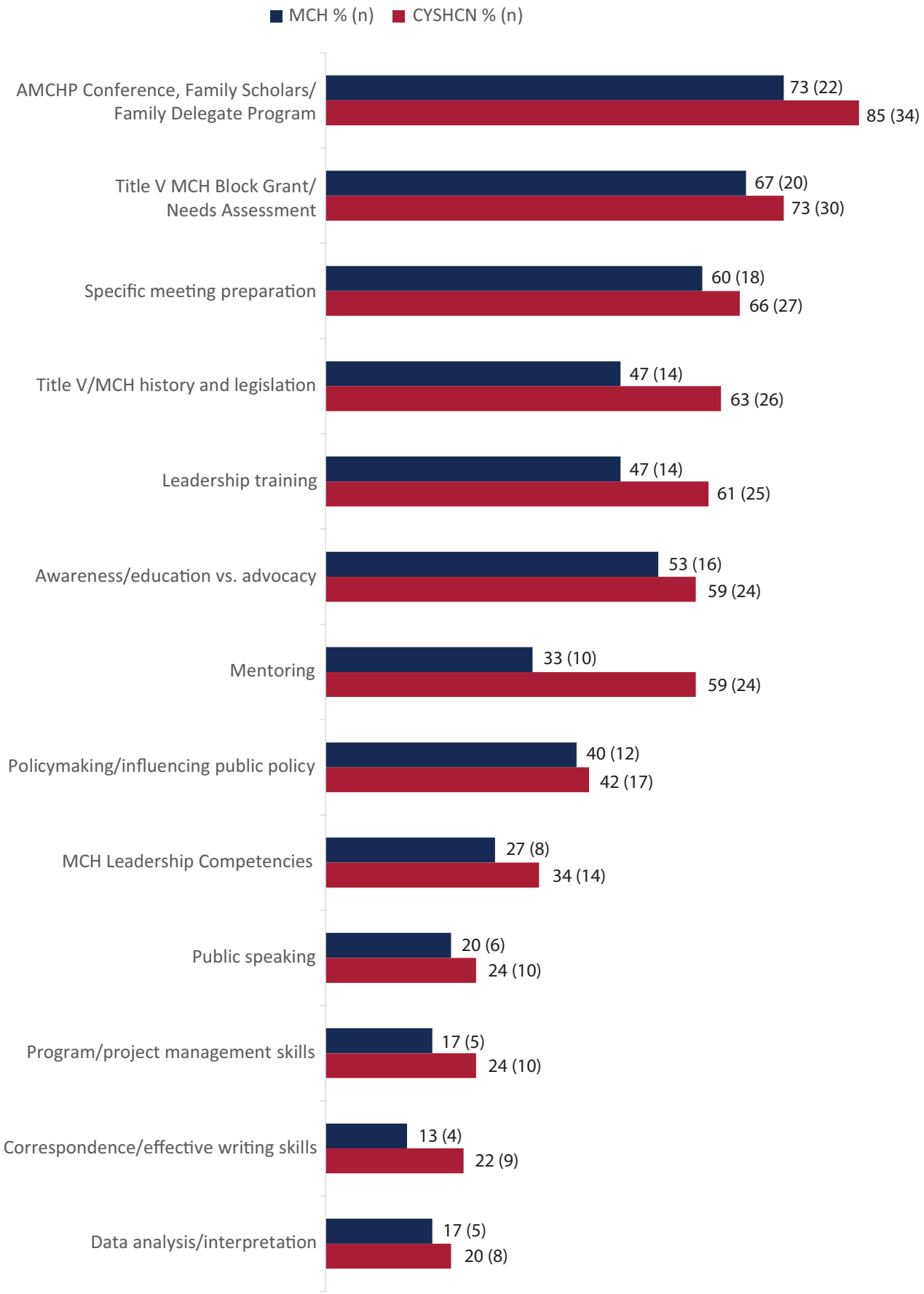
NOTE: 34 MCH respondents answered this question; 43 CYSHCN respondents answered this question.

Financial Compensation for Family Representatives on Advisory Groups

Compensation Type	MCH % (n)	CYSHCN % (n)
Honorarium/stipend*	34 (12)	57 (24)
Hourly wage*	9 (3)	14 (6)
Transportation stipend/ mileage reimbursement**	71 (24)	67 (29)
Child care stipend**	21 (7)	30 (13)

* Note: 35 MCH respondents answered this question; 42 CYSHCN respondents answered this question
** Note: 34 MCH respondents answered this question; 43 CYSHCN respondents answered this question

Training for Families Engaged with Title V Programs



NOTE: 30 MCH respondents answered this question; 41 CYSHCN respondents answered this question.

Evaluating Family Engagement in 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.[1] 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 shares methods for evaluating family engagement as well as barriers and benefits to engaging families.

Methods for Evaluating Family Engagement

The survey data corroborate anecdotal reports that evaluation of family engagement efforts is an underdeveloped area of program improvement, and that Title V programs recognize a need to develop their capacity in this regard. From a list of family engagement-related training and technical assistance topics, "methods to evaluate the extent, impact, and effectiveness of family engagement" ranks among the top two needs identified by CYSHCN programs and in the top four identified by MCH programs; 47 percent (17) of MCH and 63 percent (25) of CYSHCN respondents reported needing assistance with evaluation of family engagement.

Nearly twice as many MCH respondents as CYSHCN respondents report having no method to evaluate the impact and effectiveness of their programs' family

engagement activities. The most common method used by both programs is participant satisfaction surveys. More than twice as many CYSHCN as MCH respondents use data from outside family organizations for this purpose. While similar percentages from both programs report using internal self-assessments without family participation, the percentage of CYSHCN respondents reporting that families are involved in internal self-assessments is more than double that of MCH respondents. CYSHCN programs also are more likely to use external review or assessment by families, youth, advisory groups, or family organizations as a method of evaluating family engagement.

Only four states indicated that their Title V programs use a comprehensive approach to evaluation with standardized indicators of family engagement.

[1]Total n for individual survey items varies due to skip patterns and nonresponses.

Response Rates by Region

Evaluation Method	MCH % (n)	CYSHCN % (n)
No evaluation methods	31 (11)	15 (6)
Participant satisfaction surveys	47 (17)	70 (28)
Data from outside family organizations	25 (9)	60 (24)
Internal self-assessment – program staff not including families	22 (8)	20 (8)
Internal self-assessment – program staff including families	19 (7)	45 (18)
External review/assessment by families, youth, advisory groups or family organizations	8 (3)	25 (10)
Comprehensive approach to evaluation with standardized indicators of family engagement across programs within agency	3 (1)	8 (3)

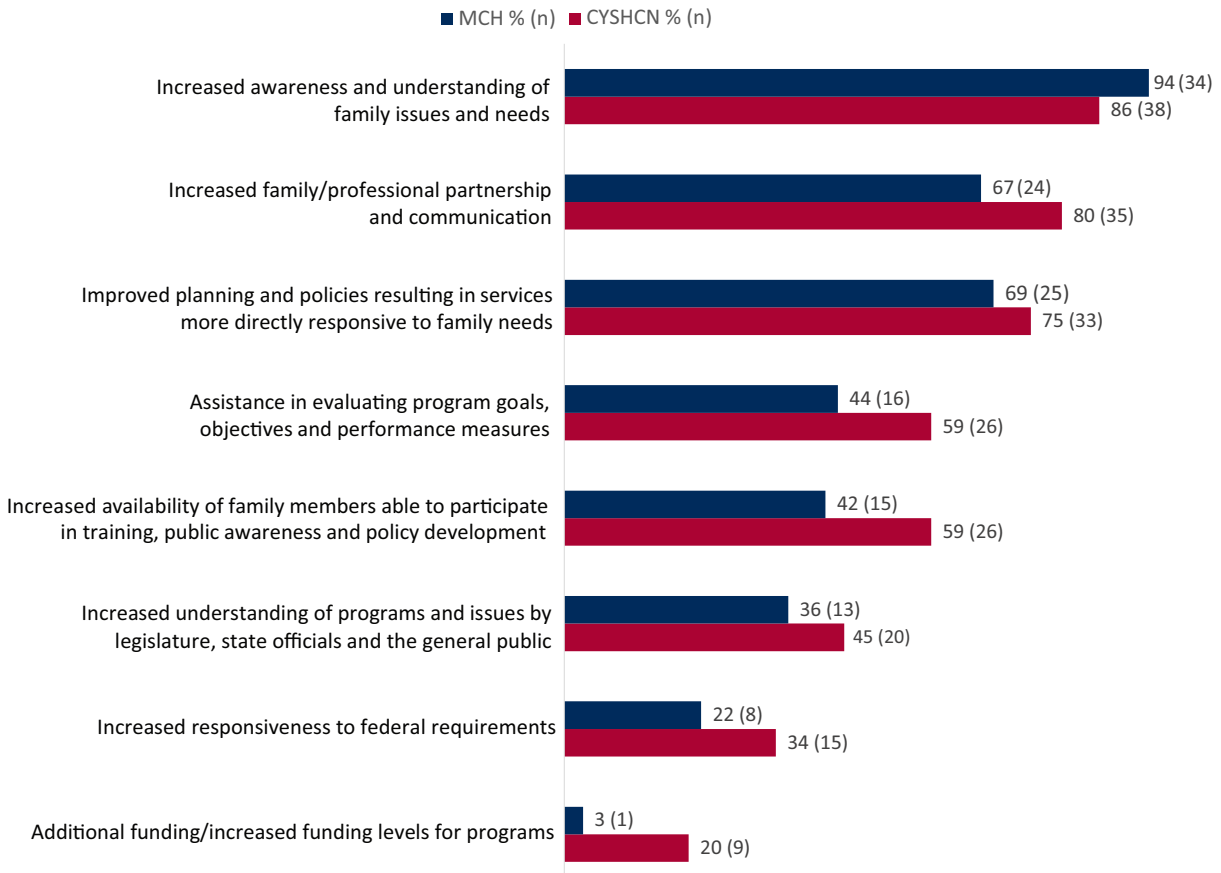
NOTE: Percentages based on 36 MCH responses and 40 CYSHCN responses this question.

Effects of Family Engagement: Benefits and Barriers

Benefits of Family Engagement
Respondents were asked about noticeable or tangible benefits their programs had experienced as a result of family engagement. They were prompted to consider only benefits their programs had actually experienced, not theoretical benefits. The top three benefits identified by both MCH and CYSHCN respondents are:

- Heightened awareness and understanding of family issues and needs
- Increased family/professional partnerships and communication
- Improved planning and policies resulting in services more directly responsive to family needs

Perceived Benefits of Family Engagement



NOTE: Percentages based on 36 MCH responses and 44 CYSHCN responses this question.

What specific program areas or issues have received the biggest benefit from family engagement? *(Only program areas/issues identified by multiple respondents are included here. Numbers of mentions are in parentheses.)*	
MCH Respondents	**CYSHCN Respondents**
Care coordination and navigating system of care (11) CYSHCN (includes specific CYSHCN program planning and system improvement activities) (10) Adolescent health (6) Medical home (6) WIC (6) Emergency preparedness (3) Newborn Screening/Newborn Hearing Screening (3) Safe sleep (3) Transition (3) Early Intervention (2) Perinatal health/improving pregnancy outcomes (2) Child health (2)	CYSHCN (includes specific CYSHCN program planning and system improvement activities) (14) Medical home (13) Family support programs/networks (11) Care coordination (10) Transition (8) Emergency preparedness (5) Newborn Screening/Newborn Hearing Screening (5) Early Intervention (2) Safe Sleep (2) WIC (2)

Respondents were also asked to identify specific program areas or issues that have experienced the biggest benefits from family engagement. (Chart above.) This question was open-ended, and respondents were free to list as many program areas or issues as they wished. Responses were submitted by 24 MCH and 34 CYSHCN programs.

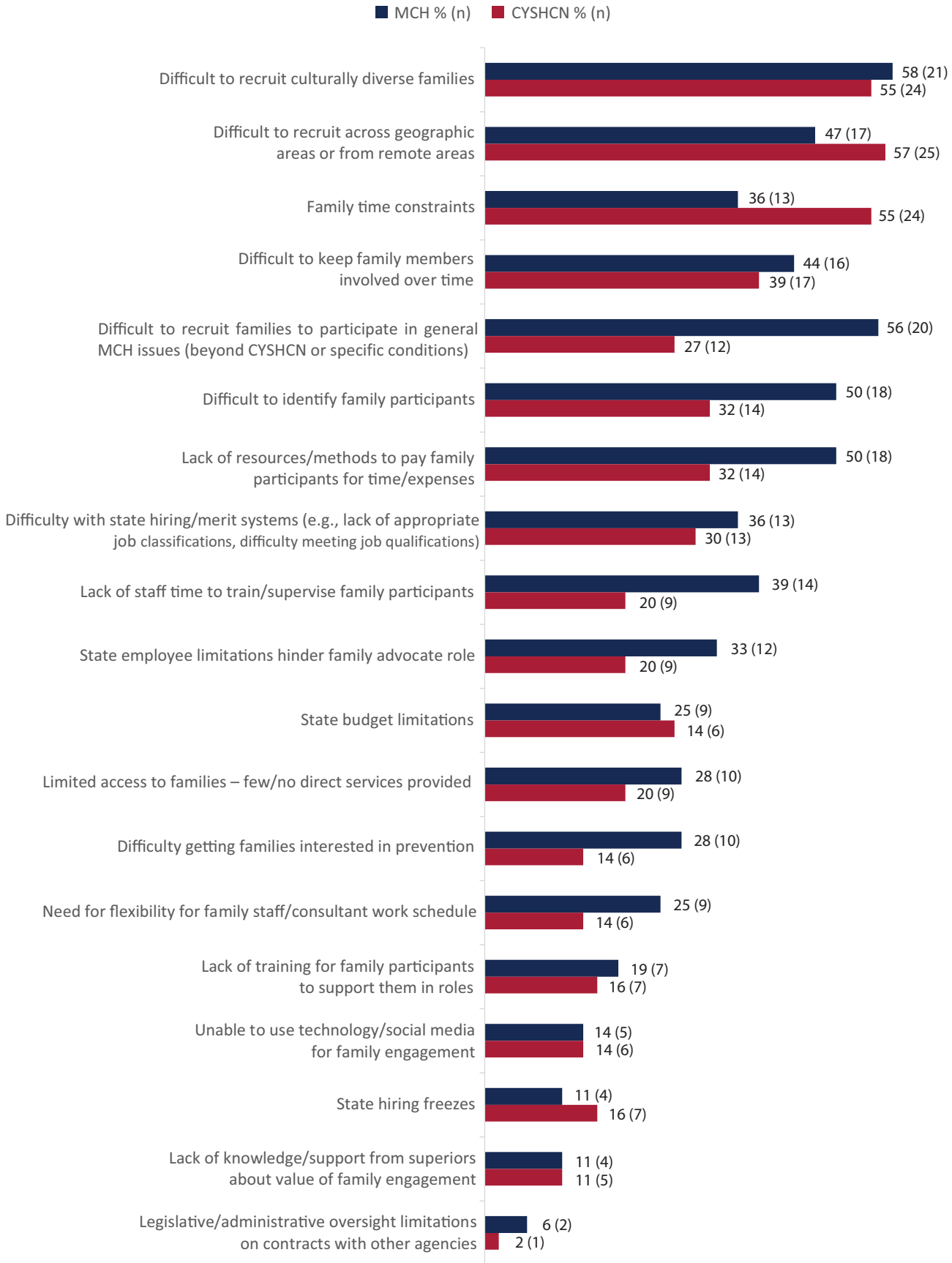
Barriers to Family Engagement

As with benefits, respondents were asked to identify barriers to family engagement that their programs had actually experienced (as opposed to theoretical difficulties). The top difficulties experienced by both MCH and CYSHCN programs include:

- Recruiting representation across geographic areas or from those in remote areas
- Recruiting culturally diverse families
- Identifying family representatives
- Lack of resources or methods to pay family participants for time or expenses
- Keeping family members involved over time

Family time constraints also rank among the top barriers identified by CYSHCN respondents. For MCH respondents, recruiting families to participate in more general MCH issues (beyond CYSHCN or condition-specific committees) is the second-most often identified challenge.

Perceived Barriers to Family Engagement



NOTE: Percentages based on 36 MCH responses and 44 CYSHCN responses to this question.

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