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

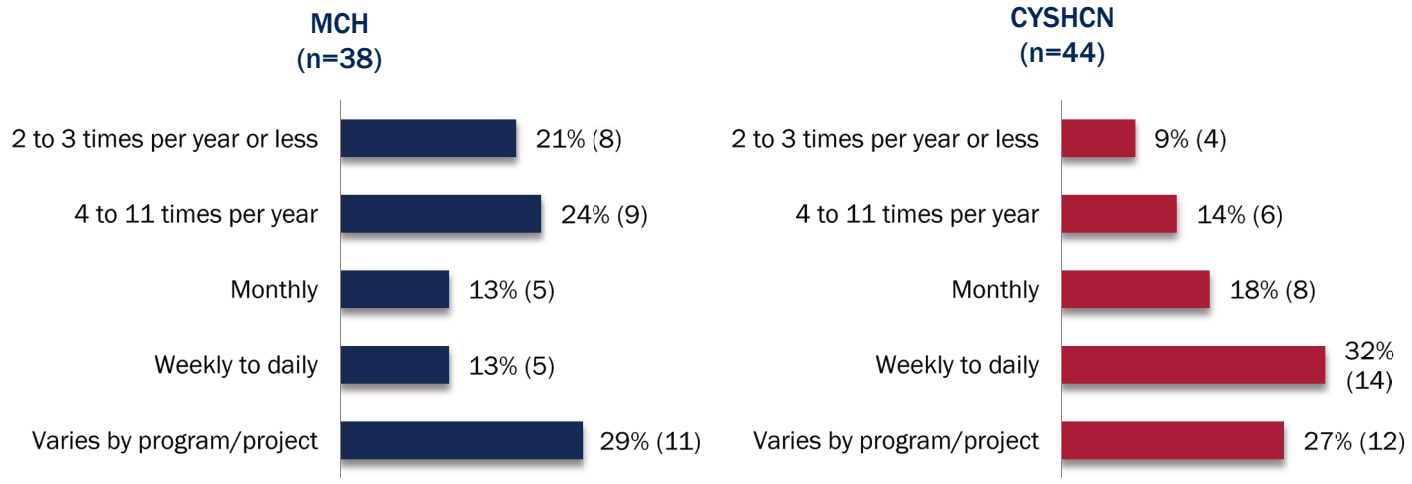
	CYSHCN % (n)	MCH % (n)	
Partnerships with family organizations	98 (43)	84 (32)	Representatives on advisory groups
Representatives on advisory groups	91 (40)	82 (31)	Partnerships with family organizations
Surveys/satisfaction surveys	89 (39)	76 (29)	Surveys/satisfaction surveys
Family representatives 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)

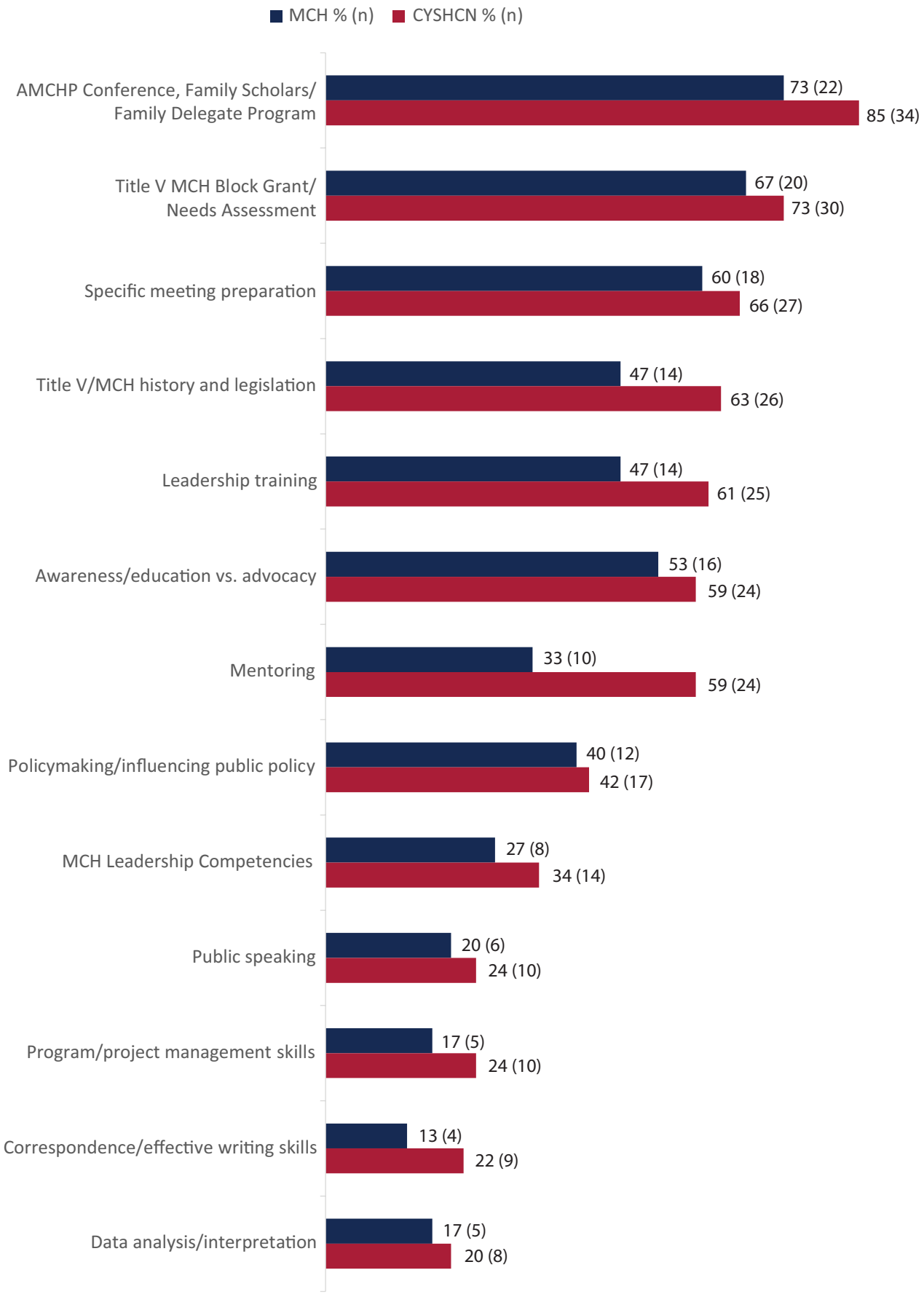
NOTE: 34 MCH respondents answered this question; 43 CYSHCN respondents answered this question.

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.