July 2016

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. 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).

Families are in leadership roles to partner with other program staff in decisions related to program planning and policymaking. Family engagement is part of the program culture; it is expected and institutionalized with clear guidelines.

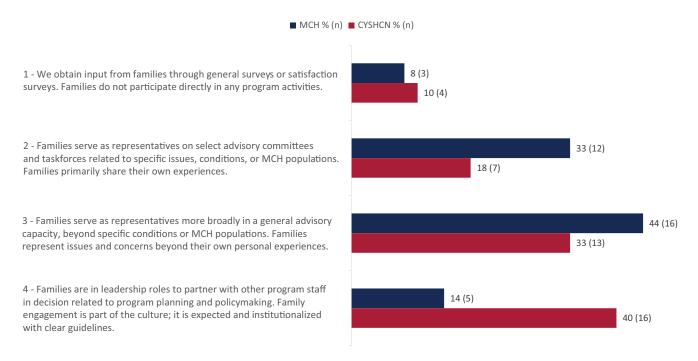
Families serve as representatives more broadly and in a general advisory capacity, beyond specific issues, conditions or MCH populations. Families represent issues and concerns beyond their own personal experience.

Families serve as representatives on select advisory committees and taskforces related to speci fic issues, conditions or MCH populations. Families primarily share their own personal experiences.

We obtain input from families through general surveys or satisfaction surveys. Families do not participate directly in any program activities.

¹Total 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)

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	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 h ealth	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 p reparedness	2.05 (1.07-3.03)	2.37 (1.85-2.90)	Oral h ealth
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.