

AMCHP Family Delegate

Health Reform and Family Leaders

Background

The National Maternal and Child Health Workforce Development Center (the Center) at the University of North Carolina Chapel Hill, in cooperation with the Maternal and Child Health Bureau (MCHB), and in partnership with the Association of Maternal & Child Health Programs (AMCHP) along with national experts in maternal and child health (MCH) innovation and quality improvement, offers state and territorial Title V leaders training, collaborative learning, coaching and consultation in implementing health reform using a variety of learning platforms. Family leaders working in Title V play a critical role in health reform implementation - both as professionals and as consumers. The Center and AMCHP formed a family engagement team to develop strategies to address family leader workforce needs related to implementing health reform. As part of these efforts, the team worked together to develop a brief survey for AMCHP Family Delegates (FDs) to assess both their health reform knowledge and needs.

Methods

AMCHP utilized Survey Monkey, a Web-based survey program, to develop and disseminate the needs assessment survey. The questionnaire contained eleven questions and included both open-ended and closed-ended questions covering three broad areas: family leader role and responsibilities in Title V programs (including the impact of health reform on these responsibilities); understanding of and access to information on health reform; and, learning needs/preferences for further information on health reform.

All 34 Family Delegates were sent an e-mail invitation to take the survey. Fifteen individuals completed the survey, yielding a response rate of 44 percent.

The purpose of the survey was to gather information about family leader demographics, the FD role in Title V, and their knowledge/needs related to health reform. The Center family engagement workgroup plans to utilize survey results to design strategies that will build the knowledge, skills and competencies related to health reform implementation of family leaders working in Title V.

Results

Demographics: Family Delegates from all 10 regions, including 14 states and one U.S. territory, were represented in the survey.

AMCHP Family Delegates are an active advocate for all families in their state/ territory, including families with special health care needs, and work within state, territorial, and/or community systems of care to advise, promote, and educate families and program/policy leaders on new and existing policies/programs. The role of the Family Delegate and how they work with Title V varies greatly from state to state as their responsibilities are designed to meet the unique needs of the families and programs in their state.

Title V Role: More than half of the responses indicated the FD relationship with Title V is as a paid staff member. Other responses included state team member, advisory council member, volunteer, patient navigator, and resource and referral specialist.

Responsibilities: Included in the range of responsibilities of Family Delegates were: Grant writing and coordination: Working/collaborating with other stakeholders (examples given: Family Voices, F2F, Family Advisory Council, LEND, and Parent Training and Information Center); Contract management; Needs assessment (examples given: coordinate community input, preparing/reporting/participating in review);

Identifying health priorities; Advocating for families; Engaging families (examples given: recruit/train/mentor parents, supervise parent leaders, identify families to share stories and wisdom at conferences and meetings, and provide information); and, Providing family voice (examples given: provide input on program matters, represent the population of children and youth with special health care needs (CYSHCN) at meetings and groups, participate on advisory councils, and represent the family perspective to councils/advisory groups/national partners)

Health Reform Impact on Role: Most of the respondents reported little or no change in their primary roles as a result of changes related to health reform. Of the few who have had a change in their responsibilities, the changes included gathering and tracking stories of how the Affordable Care Act (ACA) has impacted families, a broadening of domains to focus on (foster care, mental health, education, etc.), and disseminating information about insurance and health care.

Understanding of Health Reform and Access to Information: Eighty-two percent of family leaders who responded to the survey reported that they are either familiar or very familiar with how health reform is being implemented in their state.

Family leaders are getting information on health reform implementation through a variety of sources and the majority of responses indicate that the information available is adequate.

The main sources of information were other organizations or partners, media, and state specific sources. Among the organizations and partners mentioned were AMCHP, Family Voices, The Commonwealth Fund, Children's Hospital, and The Women's Foundation. Media sources included the news, the Internet and Healthcare.gov. State-based resources included State website, State-funded Navigators, State Department of Health, Office of the Insurance Commissioner, Medicaid agency, Family Advisory Council, and Title V Director.

Learning Interests and Preferences: The majority of family leaders who responded to the survey (nearly 90 percent) indicated they would be interested or very interested in receiving more information on: Quality improvement; Leading change; Integrating systems of primary care, specialty care and public health; State experiences

with health reform implementation; and, Improving access to affordable health care

About half also indicated they would be interested in more information on the basics of the ACA. Other topics mentioned were care coordination (e.g., confusion regarding role definition and best practices), transition to adulthood (e.g., young adults with disabilities and chronic health conditions to adult providers), and CYSHCN (e.g., information about mental health services).

Preferred Learning Format: A variety of learning formats were presented in a multiple-choice question that allowed respondents to select all that were relevant. By far the preferred format was fact sheets or issue briefs (selected by 82 percent of respondents), followed by webinars (53 percent) and online videos (42 percent). Workshops at the AMCHP Annual Conference were mentioned as well as MCH Navigator Spotlights.

Next Steps: Moving forward, AMCHP and the Center will be working to provide additional information, tools, and resources to Family Delegates to support their engagement in health reform.

For more information about AMCHP's role in supporting Title V Family Delegates, please contact Michelle Jarvis, Program Manager, Family Engagement and Leadership Development, at mjarvis@amchp.org.

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