

AMCHP Fact Sheet

AMCHP Family Delegate Fundamentals

What is AMCHP?

The Association of Maternal & Child Health Programs (AMCHP) is a national nonprofit organization that supports state and territorial maternal and child health (MCH) programs and provides national leadership and technical assistance on issues affecting the health of women, infants, children, adolescents and children with special health care needs.

What is an AMCHP Family Delegate?

Each Title V program paying dues may designate up to five delegates who have voting rights and the fifth delegate seat must be held by a family liaison to the Title V program. The Family Delegate is an active advocate for all families in their state/territory, including families with special health care needs, and works 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. Historically, family leaders have represented children and youth with special health care needs, it is the aim to have family representatives from all MCH programs.

Choosing a Family Delegate is a vital step toward meaningful family involvement and connecting families with counterparts across the country. At present, 31 states have Family Delegates. AMCHP urges all states/territories to appoint a Family Delegate but realizes that not all states/territories have the same capacity to involve families.

The ultimate success of any policy or program initiative depends on its ability meet the needs of families. Family Delegates are key stakeholders in their families and children's care and can serve as an invaluable resource to AMCHP, state and territorial Title V programs, the Maternal and Child Health Bureau (MCHB), and family organizations,

such as Family Voices.



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

This document serves as a guide to identify, select and support Family Delegates. The examples included are meant as considerations and not requirements.

Selecting a Family Delegate

Family Delegates can be identified through a variety of mechanisms, including consulting with program directors at the state, territorial and local level; talking to former AMCHP family scholars; contacting parent groups in the state or territory, such as state chapters of Family Voices, Parent to Parent, Healthy Start and Parent-Teacher Organizations; or looking to family members who already serve as paid family representatives or parent consultants to programs. States and territories also may consider rotating families serving as Family Delegates to AMCHP in order to build family involvement and family representative capacity in the jurisdiction.

Ideally, the Family Delegate has a proven track record as an active advocate for families through their assistance to other families and their own personal experiences in their state or territorial system of care.

Roles/Responsibilities of Family Delegates

Family Delegates have important roles and responsibilities at the local and state levels and should be prepared to advocate for involvement in some of the following activities:

- Policy development and decision-making process to assist management in determining program outcome (performance) measures, block grant review, data-collection systems, care coordination, outreach, and evaluation/assessment
- Participation on advisory boards, state committees or program council structures

- Social marketing campaigns and promotional product development (brochures, fliers, fact sheets, pamphlets, guides, needs assessment survey, opinion surveys, resource library, center service delivery systems and Web pages) and on review teams (design, delivery and evaluation of program goods and services)
- System of care processes (advise on “Best Practices” for program and its consumers, participate in a medical home or cultural competency programs)
- Advance and plan Title V program community outreach and professional development efforts (trainings, support group meetings, awareness campaigns, rallies, technical assistance, conferences, focus groups, etc.)
- Development of a peer support system or parent council of Family Delegates (national-, state- and local-level support)
- Help build a community stakeholder network
- Technical assistance to the Title V program regarding the implementation of program services, policies, procedures and strategic planning
- Advocacy, support and guidance to families relevant to navigating the Title V program system
- Liaison to families, the Title V program, AMCHP, and family or other health and human services organizations

Title V Programs Support for Family Delegate

In order for a Family Delegate to have a meaningful role, the Title V leadership must recognize him/her as an equal member of the delegation and must be committed to involving the Family Delegate on a regular basis. The Title V and CYSHCN Directors must ensure that the Family Delegate has real responsibilities and is supported through assistance with logistics, financial support and training.

Logistics may include accessible office space, resources and material; allowing for flexibility (e.g., if not on-site, include on conference calls); and/or funds and support for educational opportunities.

Financial support may include standard benefits (e.g., insurance, personal and medical leave) for Title V program part-time or full-time employees; budget or reimbursement structure for stipends, mileage/travel expenses, office/training supplies,

“Our Iowa CYSHCN program benefits greatly from the participation of our Family Delegate. Her opinions and contributions to our team provide us with the unique perspective of a family member who has navigated the complex health care system. She is a valuable member who speaks from experience, and her role in our advocacy efforts is tremendous. Our Family Delegate is viewed as an expert on the needs of our CYSHCN and their families.”

- Debra Waldron, MD, MPH
Director & Chief Medical Officer
Iowa Child Health Specialty Clinics

staff development trainings; or assistance with limited childcare expenses for family consultants.

Training may include ongoing opportunities to learn more about MCHB, Title V, the MCH Block Grant and Performance Measures at the state/territory, regional, or national levels and engaging Family Delegates in the decision-making process and program service delivery system. States may work with their Family-to-Family Health Information Centers and other family organizations to provide training for the Family Delegate if needed.

For more information on family roles within AMCHP: www.amchp.org/programsandtopics/family-involvement/Pages/default.aspx

AMCHP Supports Family Delegates

AMCHP will continue to pursue ways to strengthen support for Family Delegates by highlighting best practices, assisting with the identification and recruitment of potential Family Delegates, and working with states and territories to provide opportunities for leadership development and training for these individuals.

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