



Association of Maternal & Child Health Programs (AMCHP) Family Delegate:

A GUIDE FOR FAMILY LEADERS & TITLE V PROGRAMS



INTRODUCTION

The family delegate is an active advocate for all families in their state/territory, including families of children and youth with special health care needs (CYSHCN). Family delegates work within state, territorial, and/or community systems of care to advise, promote, and educate families and Title V leaders on new and existing policies and programs. Family delegates understand the needs of families in their state and are partners in the planning and review of state Title V programs and policies. Becoming a family delegate gives parents and other family members (grandparents, adult siblings, and others) and legal custodians with lived experience across Title V/Maternal and Child Health program the voice and opportunity to effect positive change for women and children, including CYSHCN.

AMCHP encourages each state to have a family delegate. The family delegate's role varies from state to state depending on the needs of individual Title V programs. The Title V director, CYSHCN director, other Title V program directors, and/or their designees should work collaboratively with the family delegate to determine how family delegate can contribute to their state's Title V work and how the family delegate will be compensated. Each member of this partnership should have clearly defined responsibilities and should demonstrate a high level of communication skills to keep the partnership strong.

The AMCHP Family Leadership, Education, Advocacy, and Development (LEAD) Committee is committed to making the role of the family delegate easier to understand for families. This committee also stands ready to help Title V programs identify optimal ways to engage with their family delegate to improve the Title V system in their state. With these objectives in mind and from analyzing the responses of the 2017-2018 AMCHP survey of family delegates and state Title V staff and conducting key informant interviews with a variety of stakeholders, the Family LEAD Committee members developed this guide. Findings from the survey and interviews are interspersed throughout this guide.

Key Characteristics and Experiences of Family Delegates

Results from AMCHP surveys and key informant interviews with family delegates found that:

- The majority of family delegates have lived experience as the parent of a person with special health care needs.
- Nearly half of family delegates have served in the family delegate role for two to five years.
- Most family delegates are staff of Title V programs or family advocacy agencies in their state. Examples of these programs/agencies include the Maternal and Child Health Bureau (MCHB)-funded Family-to-Family Health Information Center, Family Voices, or Parent to Parent USA.
- Many family delegates reported that they accepted this role to increase their knowledge and to be a voice to help shape policy.



FAMILY DELEGATE ROLE

Each Title V program that holds a membership with AMCHP may designate up to five delegates with voting rights, one of which is the family delegate. Title V directors may choose delegates from Title V program staff and/or family members (as defined in Section 3 of the AMCHP by-laws). However, one out of the maximum of five delegates from each Title V program may be held only by a family member.

The family delegate serves as a voice for families and children, including CYSHCN. Family delegates work with Title V programs and communities to advise, promote, and educate families and policymakers on new and existing programs impacting families. Although the majority of family delegates are family members of CYSHCN, AMCHP strives to also engage families and those with lived experience across the range of Title V/MCH programs.

The responsibilities of a family delegate vary by state, but may include any of the following:

- ▶ Participate in a Title V orientation provided by a state Title V program
- ▶ Participate on advisory boards or committees
- ▶ Develop marketing campaigns and/or educational products
- ▶ Participate in system of care processes within the state or local community
- ▶ Advance Title V community outreach and training efforts
- ▶ Develop a peer support system or network for other family liaisons and stakeholders in the state or local community
- ▶ Provide technical assistance and support to the Title V program regarding services, policies, and strategic planning, including contributing to policy development
- ▶ Provide advocacy and support to families navigating the Title V program
- ▶ Participate in advocacy training on communicating with policymakers and sharing family stories
- ▶ Act as liaison to families, Title V, AMCHP, and other organizations

- Participate in block grant writing and/or the block grant review process and the Title V needs assessment process
- Advise on family engagement initiatives
- Provide help to family leader or family advisory council activities, including facilitating meetings
- Help develop, write, and/or conduct AMCHP presentations, posters, or infographic materials
- Attend the AMCHP conference
- Exercise AMCHP voting rights

Most Common Family Delegate Activities

Results from AMCHP surveys and key informant interviews with family delegates found that the following were reported as the most common activities that family delegates participated in:

- Annual block grant review process
- Title V needs assessment process
- Consultation on Title V programs or policies outside of the block grant review

VALUE OF THE FAMILY DELEGATE ROLE

Family delegates and Title V programs can build strong partnerships that are mutually beneficial:

- Title V programs benefit from having family delegates bring their unique perspective through lived experiences. These insights can inform and drive change within the Title V program to benefit women and children throughout the state.
- Family delegates gain experience and leadership skills partnering with a variety of entities as they collaborate to effect positive change in state programs and policies. They also gain satisfaction and a sense of accomplishment from knowing that they are contributing to improvements within their state or territory that will have a lasting effect on other families and peers.

These strong partnerships can lead to improvements in how Title V programs serve families throughout the state. Family engagement strengthens the value and relevance of AMCHP's program and policy initiatives.

The family delegate opportunities within each state may include but are not limited to:

- Serving as a liaison to other families in the state/territory

- Connecting families with colleagues across the U.S.
- Being a key stakeholder in their family's and child(ren)'s care and serving as a valuable resource to AMCHP and Title V programs
- Learning how to educate non-family staff about family engagement at all levels
- Helping set state priorities
- Attending conferences and trainings
- Co-leading projects with Title V staff
- Participating in Annual MCH Block Grant writing and review process
- Assisting with the Title V Needs Assessment
- Providing consultation to Title V programs outside of the block grant review
- Getting involved as a member in the AMCHP organization
- Advocating to state and national policymakers
- Helping develop a peer support system or parent council of family delegates (national-, state-, and local-level support)
- Helping build a community stakeholder network

Title V program directors and family delegates can work together to determine additional available opportunities.

In addition to opportunities within each state, AMCHP provides the following for family delegates:

- Voting in the election of AMCHP officers and directors
- Eligibility to be elected as officers and directors
- Voting on other actions taken at any annual AMCHP regular or special meeting of members
- Participation in regional meetings and calls
- Serving on an AMCHP committee
- Encouragement to attend the annual AMCHP conference, which includes sessions designed for family delegates and families



RECRUITMENT

Title V Program Directors Seeking Family Delegates

Title V program directors have several ways to identify and recruit families/individuals who use Title V services and supports to become a family delegate. One of the most common methods is through a family or parent leadership organization within each state, such as:

- A state chapter of Family Voices
- MCHB-funded Family-to-Family Health Information Centers
- Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs
- Parent to Parent USA
- Healthy Start
- Parent-teacher organizations and other parent leadership programs.

These programs and organizations can help identify potential family delegates both from staff members and family members served by the program or organization.

Another strategy for recruiting family directors is to connect with the following individuals:

- Family members who already serve as paid family representatives
- Parent liaisons
- Family engagement specialists
- Graduates of parent leader training programs
- Members of parent advisory groups
- Parent consultants to health programs

Other good recruitment resources in the state are AMCHP's family leadership specialist or graduates of the AMCHP family leader cohort.

Although the family delegates benefit from interaction with their state's system of care, it is critical for the family delegate also to be able to look beyond their personal experience to examine and analyze how changes to policies or program services and supports may affect the population served more broadly.

Creating a role or job description for the family delegate position within a Title V program can be helpful in identifying interested and suitable candidates. Key information to consider including in this description is as follows:

- Designation of part time or full time, or number of hours per week dedicated to the role. (Knowing the necessary time commitment is especially helpful for family delegates who are staff members at another organization or agency.)
- Identification of the family delegate's role in specific activities or initiatives
- Training opportunities.
- Compensation—for time, travel, training, or other activities.

Family Leaders Interested in Becoming a Family Delegate

Usually, a family member or caregiver is invited to serve in this role by their state Title V program director. Some states may also have an application and selection process for parents or caregivers who are interested in serving as an AMCHP family delegate. In other instances, a parent or caregiver may volunteer to serve in this role, especially if they are familiar with, or have been served by, a state Title V program in the past.

Parents who are interested in becoming an AMCHP family delegate should contact their state Title V director or the director of the Title V program that serves or served their family member (e.g., maternal health, infant health, adolescent health, CYSHCN programs) for additional information and to determine whether the family delegate role is available in their state.



TRAINING AND ORIENTATION

For family delegates to feel confident and effective as a key advisor, they must receive an orientation and some basic training about Title V and the services and supports offered. The Title V director, program director, or their designee should administer the orientation. The orientation should occur within a few weeks after the individual becomes a family delegate. The initial orientation should include a workplan that is developed between the Title V program staff and the family delegate. The workplan should clearly outline the expectations for both parties and should be provided to the family delegate in writing. Family delegates will also need to know about additional training opportunities and supports to be offered by Title V.

A review of AMCHP surveys of Title V staff and family delegates and Family LEAD Committee key informant interviews of family delegates found that:

- Less than half of Title V program directors provide a formal or informal training or orientation to new family delegates.
- Approximately one third of family delegates surveyed stated that they received orientation to the family delegate role; fewer than one third received no specific training or support.

- Many family delegates do not understand the difference between their role as a family delegate and that of other family leaders in their state; they would like clearer and better-defined roles and expectations.
- A little more than one third of family delegates surveyed received an introduction to the block grant review process.

These findings demonstrate that Title V program directors should ensure that family delegates receive training and orientation on the following topics:

- State history of the Title V program
- Current Title V goals and objectives (covered in the state plan)
- The block grant review process
- Leadership development
- Role of families in Title V
- MCH Leadership Competencies
- Clear guidance on the roles and responsibilities of the family delegate (including timelines for completion of any activities), highlighting key differences between the role of a family leader versus a family delegate (including timelines for activities)
- Supports (including compensation) that the Title V team will provide to the family delegate
- The process and frequency of calls and meetings
- Expectations related to the family delegate's attendance and role at the AMCHP Annual Conference



ONLINE RESOURCES FOR FAMILY DELEGATES

The AMCHP website contains resources to help family delegates prepare for their new role. Among these are the AMCHP Fact Sheet – [AMCHP Family Delegate Fundamentals](#).

Family delegates may also benefit from participating in key [MCH Navigator Training](#) sessions such as Public Health 101 and other MCH Leadership Competencies.



FAMILY DELEGATE SUPPORT

The Title V program should acknowledge the time, effort, and value of family delegates. Title V programs support family delegates in these ways and others:

- A stipend or financial support for the family delegate's time
- Coverage of travel expenses
- Salary/hourly wages as a Title V employee
- Including them in email listservs or newsletters
- Regular check-ins with other family representatives
- Regular check-ins with state/territory Title V program staff
- Including the family delegates in meaningful activities

The type of support provided to family delegates will vary by state and territory. However, the majority of family delegates surveyed said that their role was financially supported by a family-led organization within their state/territory (such as Family Voices or the MCHB-funded Family-to-Family Health Information Center). Both Title V program directors and family delegates also shared reimbursement costs for travel expenses as another common form of support.

Title V programs and family delegates should work together to identify ways to meaningfully support the family delegate role. Connecting family delegates to other state family delegates through AMCHP is important, so they have access to training and networking opportunities. Connections can occur through the Family Leader Cohort, the Family Leader Champions for Title V Facebook page, and the Family LEAD Committee.



RECOMMENDATIONS FOR STRENGTHENING THE FAMILY DELEGATE ROLE

The following recommendations are designed to help both the Title V staff and the family delegates to work in partnership to strengthen the role of the family delegate. These broad suggestions can help establish clear expectations and maximize the family delegates contribution to improvements in Title V program services and supports to the residents in their state/territory. Title V programs and family delegates should work together to:

- Outline clear roles and responsibilities for family delegates; as well as the funding support and training to be provided.

- Clarify the difference between family delegates and family leaders.
- Frequently review the AMCHP family engagement section on the AMCHP website for updated information.
- Commit to establishing a meaningful family delegate role and to ensuring the role is filled. Family delegates bring knowledge from lived experiences to the Title V team to help them develop, implement, and monitor programs that will benefit families in states/territories, and family delegates gain leadership skills and build partnerships.
- Ensure family delegates receive training on Title V history and current activities within the state.
- Identify a consistent Title V program point of contact for family delegate guidance and support as needed.
- Establish creative ways to support the family delegate's role even when financial assistance is not available, such as developing a list of activities with an opportunity for meaningful family delegate participation.
- Share best practices and lessons learned regarding the family delegate program with other Title V program directors and family delegates.
- Have fun and realize that family delegates are helping to make positive changes for the Maternal and Child Health system!



FREQUENTLY ASKED QUESTIONS

What experience would be beneficial for the family delegate role?

- Experience serving as an advocate for families and building partnerships and collaborations at the community and/or state level.
- Willingness to partner collaboratively with Title V programs to make positive changes for women, children, and those with special health care needs.

Is there any financial support for the family delegate role?

- Financial support for family delegates varies by state and local community. Often financial support includes stipends and reimbursement for travel expenses, supplies, trainings, and childcare. Most often, family delegates are working in family-led organizations or they are Title V program employees and receive pay and standard benefits.
- As a family representative, family delegates receive the benefit of a discounted registration rate to the AMCHP conference.

Is there a limit on how long someone can serve as a family delegate?

- ➡ Typically, no. However, a state or territory may have pre-set term limits for family delegates. One of the benefits of not having a time limit is to allow ample time for the family delegate to build rapport with the Title V program staff. The benefit of rotating family delegates every few years is to build the family leadership capacity in the state or local community.

How do family delegates connect across states and territories?

- ➡ AMCHP maintains a list of family delegates who receive email blasts from the organization.
- ➡ One great way to connect with other family delegates is to encourage the family delegates to attend the AMCHP Annual Conference.
- ➡ The AMCHP Family LEAD Committee often provides opportunities to connect with other family delegates via webinars and other activities.



SUPPORTS AND RESOURCES

[Association of University Centers on Disabilities](#)

The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. AUCD has a [Family Support SIG](#), which engages the AUCD network in moving Family Support and Leadership forward at the national and state level and in advancing leadership in supporting families as part of the core work and values within the UCEDD and LEND programs.

[Be Strong Families](#)

Be Strong Families partners to create transformative change by developing and sustaining conversations that nurture the spirit of family, promote well-being, and prevent violence.

[Catalyst Center](#)

The Catalyst Center is a national center dedicated to improving health care coverage and financing for children and youth with special health care needs.

Infographic: [Family Engagement and Children and Youth with Special Health Care Needs](#)

[Family-to-Family Health Information Centers](#)

Family-to-Family Health Information Centers are family-led centers funded by the Maternal and Child Health Bureau at Health Resources and Services Administration (HRSA). Each state and the District of Columbia has one Family-to-Family Health Information Center. Each center is staffed by highly skilled, knowledgeable family

members who have first-hand experience and understanding of the challenges faced by other families of children and youth with special health care needs. These uniquely qualified staff provide critical support to these families, and particularly for those caring for families of children with complex needs and those from diverse communities.

[Family Voices](#)

Family Voices is a nonprofit, family-led organization that promotes quality health care for all children and youth, especially those with special health care needs. Working with family leaders and professional partners at the local, state, regional, and national levels since 1992, Family Voices brings a respected family perspective to improving health care programs and policies and ensuring that health care systems include, listen to, and honor the voices of families.

[Got Transition](#)

Got Transition® is the federally funded national resource center on health care transition. Its aim is to improve the transition from pediatric to adult health care through the use of evidence-driven strategies for clinicians and other health care professionals; public health programs; payers and plans; youth and young adults; and parents and caregivers.

[Hands & Voices Family Leadership in Language and Learning \(FL3\)](#)

Hands & Voices is a parent-driven and collaborative organization. Members are parents of ASL signers, cued speech users, parents of children with cochlear implants, and of children who are total communicators. Our children may be using their hands and/or their voices. The organization is comprised of individuals who have common interests connected through the community of deafness. Hands & Voices is a safe place to explore options, discover new resources, learn from one another, and share what we have in common. Hands & Voices believes that we have more that unites us than divides us.

[Health Resources and Services Administration](#)

The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary federal agency for improving health care to people who are geographically isolated, economically or medically vulnerable.

[Lucile Packard Foundation for Children's Health](#)

The Lucile Packard Foundation for Children's Health family engagement program area supports family leaders by encouraging them to become advocates who participate in all levels of clinical care and health policy advocacy and to participate meaningfully in these areas. The foundation has published the following:

Issue Brief: [A Framework for Assessing Family Engagement in Systems Change](#)

Families of children and youth with special health care needs have unique perspectives about the complexities of systems of care, arising from their involvement with so many aspects of these systems. The field widely agrees that family involvement is valued at the systems level of health care—where policies, programs, and services are created or changed. However, rarely are families given more than a token amount of power and influence. This issue brief provides an assessment tool that features four domains and specific criteria that organizations can use to measure the level of family engagement in their work.

Fact Sheet: [Engaging Families in Improving the Health Care System for Children with Special Health Care Needs](#)

A review of relevant literature on patient and family engagement finds that currently most family engagement activities occur in physicians' offices, hospitals, and clinics. Families need and have opportunities to be engaged within the broader health care system and contribute to public policy decision-making. Involving families in program and policy planning increases the likelihood of having appropriate and well-utilized services. This fact

sheet outlines the barriers to family engagement and the opportunities to improve it at all levels of the health care system.

[Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\) Programs](#)

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs provide long-term, graduate-level interdisciplinary training as well as interdisciplinary services and care. The LEND training program is designed to improve the health of infants, children, and adolescents with disabilities. The program accomplishes this by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and ensuring high levels of interdisciplinary clinical competence.

[Maternal and Child Health Bureau Title V Block Grant Program](#)

As one of the largest federal block grant programs, Title V is a key source of support for promoting and improving the health and well-being of the nation's mothers; children, including children with special needs; and their families.

[MoMMA's Voices](#)

MoMMA's Voices is a national coalition of patient organizations and individuals with "lived experiences" – or those that represent them – using their voice to reduce maternal complications in pregnancy and the postpartum period.

[National Center for Family Professional Partnerships](#)

This center provides leadership in helping families of children and youth with special health care needs/disabilities and professionals partner to improve care.

[The National Genetics Education and Family Support Center](#)

The National Genetics Education and Family Support Center was a three-year initiative (June 2017 through May 2020) led by an organization named Genetic Alliance in partnership with the Regional Genetics Networks, Family Voices, and Parent to Parent USA. The focus of Family Support Center is to build a network of partners and develop accessible tools to improve access to and the quality of genetic services.

[National Parent Leadership Institute](#)

The National Parent Leadership Institute is a parent-centered, anti-racist organization that partners with parents and communities to equip families with the civic skills, knowledge, and opportunities to be leading advocates for children at home, school, and in the community.

[National Parent Teacher Organization](#)

The National Parent Teacher Organization serves as an advocate to help parent teacher organizations or parent groups succeed.

[National Resource Center for Patient/Family-Centered Medical Home](#)

The goal of the National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH) is to improve the health and well-being of, and strengthen the system of services for, children and youth with special health care needs and their families by providing technical assistance and support in implementing the patient/family-centered medical home model. The NRC-PFCMH website has several tools and resources related to family engagement.

[National Adolescent and Young Adult Health Information Center](#)

The National Adolescent and Young Adult Health Information Center aims to improve the health of adolescents and young adults (AYAs) by strengthening the capacity of state Title V MCH Programs and partners to address the needs of AYAs (ages 10 through 25).

[Parent to Parent USA](#)

This organization provides emotional support and information for families of children who have disabilities and special health care needs. For more than 36 years, Parent to Parent programs across the country have been providing this support, most notably by matching parents seeking support with an experienced, trained “support parent.”

[Preeclampsia Foundation](#)

The Preeclampsia Foundation is an empowered community of patients and experts, with a diverse array of resources and support to help you have the best possible pregnancy or to help you navigate the questions you’ll have if you don’t. We provide unparalleled support and advocacy for the people whose lives have been or will be affected by the condition – mothers, babies, fathers and their families.

ACKNOWLEDGEMENT

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U01MC00001 Partnership for State Title V MCH Leadership Community Cooperative Agreement (1,884,467.00). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government