Family Engagement in Title V
WHAT IS FAMILY/CONSUMER PARTNERSHIP?

The Title V MCH program expressly seeks to implement family centered, community-based systems of coordinated care for CYSHCN. At its most basic, family centered care is the partnership between families and professionals at all levels working together for the best interest of the child and the family. The Title V Block Grant defines family/consumer partnership as “the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level.” Family/consumer partnership is a myriad of activities that engages families into partnership with systems and services to ensure that they are working in the best interest of the children and families they are intended to reach. All the aims of MCH programs are best met with the involvement of the families impacted by the policies, systems and services they touch. The Latin phrase *Nihil de nobis, sine nobis* (Nothing about us without us), a slogan used by the disability rights and parent leadership movement, touches on the idea that no policy should be decided without the full and direct participation of those affected by that policy. As MCH professionals we see firsthand the impact of this philosophy through the work of family leaders involved in all levels of MCH.

Including families at all levels is the right thing to do! Successful businesses have known for decades that consumer input is invaluable to developing goods and services that the public will buy. MCH can put those same marketing principles to use in planning services and allocating scarce resources. We can ensure that our services are targeted to best meet family needs without wasting funds on unnecessary frills or errors in judgment about what we think families want and will use. Families can be our program target marketers who know where and how to reach underserved families. Families are better able to use services if they are educated and aware of their options.

A critical part of promoting family centered care is ensuring programs are structured to support and engage families in planning, development and evaluation. The needs assessment, consumer advisory boards and public comment processes that are cornerstones of MCH programs are opportunities for meaningful engagement. In order to ensure that programs reflect the needs of the populations served, it is imperative to partner with families during the design and implementation phases. While these activities are important, true family/consumer engagement and family centered care cannot be a series of points-in-time contacts with limited representation of families; instead they result from a continuous commitment to partner with families, instead of simply serving families. It is critical that partnership includes the diversity of families served within your state. Programs benefit from diverse geographical, socioeconomic and cultural perspective.

How MCH programs operationalize family/consumer engagement differs significantly from state to state, reflecting the variability of communities. As a part of the commitment to involvement, programs may hire family
representatives on staff. Family professionals are an important part of the MCH workforce, bringing with them diverse backgrounds and expertise. Increasingly, highly trained MCH family leaders are developed both via their lived experience and by volunteer and professional roles in family organizations, education and other systems related to MCH and through existing MCH workforce pipeline programs. Family leaders have much to offer the programs of their organizations in all areas, including CYSHCN, immunization, injury prevention and perinatal health.

HOW TO BUILD FAMILY/CONSUMER ENGAGEMENT IN YOUR STATE

One approach to family/consumer engagement is to develop and engage parent advisory committees. Together, staff and family leaders set meeting agendas and hold meetings on a regular basis. Families can help review new policies, education materials, brochures, literature and reports. The councils may discuss policies that families find problematic, help develop the strategic plan, participate in the needs assessment, help develop the Block Grant application and provide advice on the budget. Besides policy making, families can participate in outreach work and training activities for both professionals and families.

Meaningful family/consumer engagement should include a clear commitment to be representative. While seasoned family leaders may cultivate significant connections and networks, which allow them to serve as conduits for the input of diverse families, every effort should be made to ensure family partners who possess direct current experience with systems and services provide feedback and inform continuous quality improvement. For example, a workgroup around income eligibility levels would benefit from the perspective of families who have navigated systems that require income eligibility processes. Ensuring this type of involvement takes us beyond a small pool of family leaders and family members of our MCH staff and may require some creativity to meet families in a variety of settings and in various levels of their leadership skills. Social media, online polling, text input, non-traditional meeting times, and linguistically relevant documents are some of the many strategies used to engage a broader group of families.

For families to be effective in their role as advisors to Title V programs, they – like all those new to MCH – must be provided with education about MCH broadly, and the Title V Block Grant. Take the time to ensure they are oriented completely so they feel comfortable and able to participate fully in Block Grant reporting and/or reviews. A mentoring system whereby seasoned family advisors and professional staff provide training to new family advisors, including introduction to the MCH Leadership Competencies, is an excellent approach to orientation and development of family leaders. As with all partners it is imperative to be committed to the importance of their input. When you hear someone make a great comment at a meeting, tell her or him so.

Another way for families to be engaged is by serving as an AMCHP Family Delegate.

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WHAT IS AN AMCHP FAMILY DELEGATE?

Each Title V program paying dues at AMCHP may designate up to five delegates who have voting rights; the fifth delegate seat is reserved for a family liaison to the state or territory 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 CYSHCN, and it is the aim to have family representatives from all MCH programs. Choosing a Family Delegate is a vital step toward meaningful family/consumer engagement and connecting families with counterparts across the country. At present, more than 30 states have Family Delegates. AMCHP encourages 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, MCHB, and family organizations, such as Family Voices.

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 engagement 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 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 process (advices on "Best Practices" for program and its consumers, participate in a medical home or cultural competency programs)
- Advance the 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

COMPENSATED KEY PERSONNEL

Rather than isolating agency and family work, include them as key team members of the MCH workforce on projects, agency initiatives and learning collaboratives. Examples include seeking their participation in Action Learning Collaboratives such as Return on Investment; and as team members of project cohorts, etc.

THE VALUE OF FAMILY/CONSUMER ENGAGEMENT

Expanding family/consumer engagement in your state, engaging families to be members of task forces, advisory board members, program evaluators, co-trainers of pre-service or in-service training sessions, paid program staff, paid program or policy consultants, mentors for other families and professionals, grant reviewers, participants in the needs assessment process, reviewers of the Block Grant application, and more, can transform your capacity for family centered care.

The capacity to ensure family/consumer engagement requires that programs figure out how to compensate parents for their time. Relying only on the input of families with the resources to volunteer their time severely limits the perspectives represented. In addition, uncompensated participation devalues the role of family as partners. Some states use the agency contracting process to reimburse parents for their expenses. Others need to secure an administrative rule or even special legislative approval to pay parents for their participation in an advisory capacity. Explore avenues within your system that might be used, develop a proposal and get clearance from agency leadership. Contracting with a family leader as a subject matter expert is often the same administrative process a state must follow when securing a contract for specific expertise and/or outcomes.

MCH leadership at the state level has the opportunity to infuse the strength of family/consumer engagement into all levels of the system. Requests for proposals, funding and programs supported can be required to include family/consumer engagement in all steps and levels. Tying contracts to this not only provides you access to data about family/consumer engagement at the local level, it grows and strengthens the robust network of family-professional partnerships needed to ensure family centered care.

A critical value of parents familiar with the Title V programs is their ability to strongly advocate for programs that serve them well. Parents and organizations who know how to interact with legislators should be your new best friends. The old adage “make your friends before you need them” definitely applies here! Equipping families with firsthand knowledge of the budget and system challenges faced by MCH allows them to be eloquent and powerful advocates. Families who are partners in care at all levels provide a powerful grassroots network.

Tips for Successful Family/Consumer Engagement

• Identify current programs that involve parents and how they are compensated whether as salaried or contract employees or provided stipends for their time. Meet with these family
leaders to discuss their roles and identify opportunities for expanding family representation throughout the Title V programs.

• Make it your business to find out what parent groups exist in your state and invite all of them to meet with you to discuss their needs and suggestions for increasing family representation.

• Identify and address barriers to family/consumer engagement, such as transportation, travel reimbursement, cost of child care, long distance phone calls, lost wages for time spent attending meetings, etc.

• Identify and address barriers to achieving cultural diversity in family representation.

• Include funds to support family engagement within your budgets, families should receive stipends or other compensation for their contributions to your program.

• Plan how to secure or expand family/consumer engagement, ensuring cultural diversity and outreach to all groups.

• Hold regional meetings with parents, because it is easier for staff to travel to families, especially if your state is large geographically.

RESOURCES


