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# AMCHP Issue Brief

## How to Select a Family Delegate: State Examples

### 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. AMCHP reserves the fifth delegate in each state for a family liaison to the Title V program. The Family Delegate is an active advocate for all families in their state or 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.

Choosing a Family Delegate is a vital step toward meaningful family engagement and connecting families with counterparts across the country.

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 family's 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.

This document serves as a resource to identify and select Family Delegates. The examples included are considered best practices and are not requirements.

### Selecting a Family Delegate

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

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.

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.

While selection criteria and processes vary by state, below are a couple examples how other states chose their Family Delegate.

## The Family Delegate Role in Kansas

By: Heather Smith and Donna Yadrich


In Kansas, family partnership is foundational to Title V and our programs to support the MCH population. Kansas is dedicated to building strong MCH leaders and advocates and the AMCHP Family Delegate (FD) is recognized as an important role a family partner can have at the local, state and national level. The Kansas program provides families with opportunities to build leadership and advocacy skills and engage in system-level discussions regarding MCH services/initiatives. As an active advocate for all families in Kansas, including families with special health care needs, the FD has the capacity to advise, promote, and educate families and program/policy leaders on new and existing policies or programs.

The Title V CYSCHN director provides oversight to the FD program selection process, convening a review team of Title V staff to make the final determination. This opportunity is open to any Kansas parent/family member, served by a state or local Bureau of Family Health (BFH) program, interested in building leadership and advocacy skills and learning more about Title V and AMCHP. We believe parents/families can provide firsthand knowledge, insight to areas that program staff may not have considered, and recommend changes for other consumers. BFH programming is wide-spread and includes: reproductive health and family planning, nutrition and WIC services, MCH programs, newborn screenings, special health care needs services, early intervention, and child care and foster care services.

Kansas is dedicated to family engagement and believes this is a critical leadership role within Title V programming. Therefore, throughout the 12-month term, the FD may:

- Recommend outcome (performance) measures
- Participate in annual Title V MCH Services Block Grant review
- Serve on MCH-related advisory boards, committees or councils
- Assist with MCH marketing/promotional brochures, flyers, fact sheets, etc.
- Promote program activities and initiatives, especially the Kansas Resource Guide
- Advocate, support and guide families in navigating the Title V system

The FD is assigned a Title V mentor who works with the FD to develop goals and objectives tailored to meet the needs, interests, and individual expectations of the delegate and MCH program most closely to the delegate's background. The FD is asked to select a project to complete for the relevant program and participate in: at least one MCH-related board, committee or council which can be at the local, state, or national level; quarterly webinars, trainings or informational activity on a MCH topic; and quarterly Health Resources and Services Administration Region VII conference calls or meetings. A written summary of experiences through these activities is requested, as is ongoing collaboration and communication with their assigned Title V program staff liaison.

During this first year of the new Kansas program, the FD met with both the Title V and CYSHCN directors to learn about mutual interests and discuss ways to support the delegate's interests. At that time, more immersion in the Title V MCH Block Grant process was discussed and the FD has been invited to participate in the entire 2014 Title V MCH Block Grant preparation process; from a public input survey through attendance at the Region VII onsite review in August 2014.

Additionally, Kansas Title V provided the FD financial support to attend the AMCHP conference and supported the delegate's interest in attending the post conference session, the Return on Investment (ROI) Collaborative, by sending the state MCH epidemiologist and CYSHCN program manager to join the Kansas team. The FD also was invited to serve on the Kansas MCH Council, in addition to their role on the Special Health Services Family Advisory Council.

The FD program is a natural partnership between Title V and AMCHP and is expected to build strong family leaders throughout the state for many years to come.

## The Family Delegate Role in Arkansas

By: Rodney Farley


Arkansas has filled its family delegate position since AMCHP enacted the position in 2006. Having a family delegate is crucial to our role as advocates for our Title V CYSHCN program.

Our current delegate, who attended the AMCHP conference, was quoted saying, *"During the AMCHP conference, I was able to learn about maternal and child health issues as it relates to children with special health care needs. I networked with providers and families from across the country. I found it to be very educational and very rejuvenating. We conducted Capitol Hill visits where I was able to meet with both of my senator's, as well as two of our representatives in the house. I brought letters from my friends that have children with special needs and told the importance of the Title V program and how it had helped me and continues to help me and my family. I know it made an impact."*

In Arkansas, we select our family delegate from our Parent Advisory Council (PAC), which was started 24 years ago. Arkansas PAC is a diverse group of parents of children with special health care needs from all over the state. The PAC is committed to advocating and educating other families, government agencies and health care professionals on issues that affect children with special health care needs. Their mission is simply to serve as a liaison between the families and existing resources.

The family delegate is the president of our PAC, and elections are held for that position every two years. One can only be reelected for one additional term. Typically, our PAC presidents are among the veterans on the council. It is required that the FD is a parent/family member or guardian, because the state understands that the benefits to having a parent/family member or guardian serve in this role are critical to the services they receive from the Title V MCH Services Block Grant for children and youth with special health care needs. They provide input on current services and how we can improve those services and makes them more family friendly.

Our PAC has an orientation for all new members, consisting of the "Getting to Know Title V" booklet produced by Family Voices several years ago. Another publication we use from HRSA is *Understanding Title V of the Social Security Act*. Both of these booklets, in conjunction with education from our Parent Consultant and Title V director keeps our family delegate well informed.

The family delegate that attends the AMCHP conference is expected to conduct hill visits and, after returning from the conference, write an article for our Title V CYSHCN newsletter and they must also present a power point presentation to the PAC at one of their quarterly meetings. The Parent Consultant helps them with the presentation and provides the equipment for the presentation. They also become the cheerleader for the PAC, encouraging other members to advocate right here in our state. They also have a better understanding of MCH issues after attending an AMCHP conference and help with the different forms in the Title V MCH Block Grant writing process.

In past years, before family delegates were instituted, we encouraged our families on the PAC to apply for a family scholarship to attend and participate in an AMCHP conference and hill visits. We would be glad to answer any questions other states might have about our Family Delegate or our Parent Advisory Council.

**For more information on family roles within AMCHP: Pathways-Jan2017.pdf**


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