Title V Block Grant
The Importance of Family Reviewers

Background
There is a rich history of families being engaged in Title V. In fact, maternal and child health (MCH) was born from advocacy for women and children. Dating back to 1921, we see the official beginnings of legislation focused on maternal and child health with the Sheppard-Towner Act, originally named the Maternity and Infancy Care Act. This was innovative legislation, being the first federal aid program for states regarding health. This legislation was only in effect until 1929; however, it set the stage for passage of Title V of the Social Security Act shortly thereafter, in 1935. Title V funds made it possible for states to provide programs and resources around maternity, infant, child care, and medical services for children.

Partnering with families in decision making around practices and programs that impact the health and well-being of their families is critical to ensure high quality services. This concept, called family centered care, is an important aspect of the Title V MCH Services Block Grant. Language from the appropriations for the Title V MCH Block Grant specifically speaks to family centered care and children and youth with special health care needs (CYSHCN) in the following: “...(D) to provide and to promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3) of this section) for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families;…”

History of Family Engagement in the Title V MCH Block Grant
Family members are an important source of feedback in the Title V MCH Block Grant review process. Families first became engaged as reviewers in 1997, largely as a result of Dr. Peter van Dyck, associate administrator for the Maternal and Child Health Bureau (MCHB) from 1998 to 2011, and his recognition of the value of family input and commitment to integrating families into the review process.

Leadership at MCHB also recognized the importance and value of involving families in the planning and delivery of MCH services. Having family representatives as reviewers provides each state with critical feedback regarding their plans and accomplishments from the perspective of the families they serve. States are expected to work closely with family/consumer partners in all aspects of their Title V MCH Block Grant work. The engagement of family representatives as part of the review process reaffirms the value of family leadership and provides states with feedback from the family perspective on all aspects of the block grant application/annual report.

As block grant reviewers, families participate in reviewer training and receive compensation. In addition, MCHB project officers are available to provide family reviewers with additional individual assistance, as needed, as they prepare for the block grant reviews.

A Family Leader’s Experience
By: Carmen Boucher, RI
2012 AMCHP Family Scholar Program Alumni

My first exposure to Title V was as a parent of a child with special health care needs and later as an employee of an advocacy agency (Rhode Island Parent Information Program) that encompassed Family Voices and Family to Family. My actual involvement began through my placement as a family resource specialist supervisor at the Rhode Island Department of Health, Office of Special Needs. As part of my position, I was encouraged to
attend meetings, actively participate (eventually lead) the community input process, and to attend the Title V MCH Block Grant Review.

It was in this position that I applied and was accepted to the Family Scholar Program (FSP) and learned about the Title V application process and attended a Title V review as a family representative for Rhode Island. This experience was the beginning of my intense interest in all of the different aspects of Title V and the work being accomplished in my state.

During my training as a family scholar I learned more about the role of families in the Title V application process as well as their involvement in the review of the application. I was very interested to know that families can provide their perspective in different avenues such as material review, needs assessment process, increasing parent/professional communication, improving planning and policies for improvement in services and reviewing agencies block grants.

I graduated from the FSP in 2012 with a much greater knowledge of Title V programs. I had the opportunity in 2013 and 2014 to be a family reviewer for the Title V MCH Block Grant in Region 1.

My experience as a reviewer is very rewarding. I was provided with tools and access to training on how to write a review. There also was the Title V Maternal and Child Health Services Block Grant to State Program Guidance book that provided me with references for different questions I had, conference calls that explained the process and provided time for questions and answers. There is a MCH Block Grant Reviewer Guide/Template that helps prepared the reviewer for the face to face meeting with the state they are reviewing.

The template was very helpful, and assisted me as a guide and provided me guidance to keep focused during the readings of the state application. The guide provided the opportunity for points of discussion. It also reminds the reviewer of areas of general requirements. I filled out the block grant review summary statement with all the details notes and comments from the template and brought it with me to the review. As a family reviewer I was able to ask questions for clarification about the programs that the state described in the application, and provided comments and recommendations.

The day of the review I was a valued member of a team of professionals. I was one of the team members that had expertise as a family member and a family leader. To be an active member of the block grant review was a great experience and an honor. I was compensated for my time and I was treated with respect and professionalism by everyone.

I would highly recommend that other families become involved in this worthwhile process and know that the staff is available to answer your questions.

South Dakota had the opportunity of having a family member as a part of our Federal MCH Block review in 2014. While each reviewer brings a different area/level of expertise to the review team – there is something about hearing positive comments and/or suggestions from a family member that speaks louder than all the other comments. It helps you “keep your eyes on the prize”.

~ Barb Hemmelman, SD CYSHCN Director

Conclusions
Engaging families in block grant reviews provides invaluable benefits to states and the families Title V programs serve. To be active participants in Title V MCH Block Grant reviews, families need on-going investment in their training and support and connection to Title V (both at the state and national level) programs.

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