TITLE V

Since 1935 Title V of the Social Security Act has provided a foundation for assuring the health of all mothers and children, including Children with Special Healthcare Needs (CSHCN). While Title V is a federal program, it is implemented in all 59 States and jurisdictions by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services. MCHB distributes funds, provides oversight, and assists states/jurisdictions in improving their performance. States and jurisdictions must match a certain percentage of the federal funds available through MCHB, resulting in more than $6 billion available annually for maternal and child health programs across the nation. At least 30% of Federal Title V funds are earmarked for services for CSHCN. MCH programs funded by Title V are located in State Health Departments while CSHCN programs may be located with the health department or in other human service agencies. Funds are awarded to states/jurisdictions through an annual Block Grant process that includes developing an application and ensuring public input. States/jurisdictions must complete a needs assessment every five years to learn more about the needs of families they serve. The Block Grant process has been transformed in 2015, with new approaches to planning and measuring performance.

FAMILY ENGAGEMENT IN TITLE V

MCHB encourages and provides opportunities to engage families with Title V and specifies the importance of this input in the Block Grant Guidance to states. Family leaders who have experience in partnering with public health and other providers around issues for CSHCN can play an important role in ensuring that Title V funding within their state is meeting the needs of both CSHCN as well as the needs of other populations served such as pregnant women, mothers, infants, children and adolescents.
Family to Family Health Information Centers (F2Fs), programs funded by MCHB to help families of CSHCN to partner with providers to improve systems, as well as Family Voices State Affiliate Organizations (FV SAOs) are in a unique position to help Title V programs address not only the specific requirements of family engagement in the Title V Block Grant process, but to provide an ongoing perspective of family needs and that is responsive to changes in community demographics, changes brought about by new federal and state programs, and changes effected by the economy and other factors. Connect with an F2F or SAO to build your leadership skills and become an effective partner with Title V.

TIPS TO BUILD PARTNERSHIPS WITH TITLE V

The following tips are offered to help family leaders who are connected to F2Fs, FV SAOs or other family organizations develop, renew, or expand a partnership with Title V.

1. Learn more about Title V benefits to families
   - Learn as much as you can about the Title V legislation. The Family Voices website offers materials to help you such as Getting to Know Title V, Title V Information System, and more on the Family Voices website.

2. Learn more about Title V in your state/jurisdiction
   - Read your state’s most recent Title V Block Grant application.
   - Explore the Title V website for your state, if one is available.
   - Identify how your Title V program currently approaches engaging families served by their programs.
   - If you are not already in touch, connect with the F2F HIC or FV SAO in your state to learn about opportunities to partner with Title V.
   - Contact your Title V program and ask to be included on any Title V mailing and/or email lists. If you are part of a family organization with a mailing list, add MCH and CSHCN directors and other key Title V staff, including any family staff or consultants, to your mailing list.
   - Through listservs or other media announcements, learn about public meetings where Title V staff will be present and attend.
     - When you meet Title V staff, introduce yourself—ask questions, offer ideas. Share information.
     - Learn about their roles and responsibilities.

3. Find ways to work with Title V staff
   - Create opportunities for families to meet your state’s MCH & CSHCN Directors and other key MCH staff, such as family coordinators, program staff of Newborn Screening, Early Hearing Detection & Intervention, etc.
     - Plan a meeting and create an agenda that includes issues of concern to families.
Propose opportunities you can offer and ways to work together to improve services.

Talk about the role of families described in the Block Grant guidance; ask how the State is addressing these; suggest specific ways that families can be engaged in the 5 year Needs Assessment and the Block Grant process.

Share the data you collect from families about successful program and issues and concerns with MCH and CSHCN Directors.

- Participate in the Block Grant process
  - Try to be engaged in the development process.
  - Find out when the Block Grant will be ready for public review and comment. States usually hold at least one public hearing to listen to ideas about state needs and the Block Grant application.
  - Register to attend public hearings in order to share stories from families, data, and your recommendations for services and quality improvements.
  - Bring others with you!

- Participate on an Advisory Committee
  - Research existing advisory committees that are part of Title V programs in your state. Your state may have a number of committees on which it would be valuable to have family representation. Often Title V has an advisory committee for family input focused on children with special healthcare needs; other committees may focus on specific initiatives such as quality improvement, improving pregnancy outcomes, home visiting, screening, adolescent health, or smoking cessation.
  - Programs and committees that focus on specific issues/needs for the maternal or child health population, such as preventing obesity, providing home visiting services to new mothers, or improving adolescent health should also include strategies to help CSHCN and their families.
  - Ask when the Advisory Committees meet and whether they are open to the public.
  - Attend these meetings to learn more about what is needed and how to help. Volunteer to join an Advisory Committee and offer to help to recruit other families to be part of committees that address issues and policies affecting families.

State Profiles in Comprehensive Family Participation:
This 2010 AMCHP brief provides a summary of how six states (Colorado, Missouri, New Hampshire, New York, Oregon, and Washington) approach family participation, including their insights, successes and challenges:

• Mentor other families to participate on committees – including families of ethnic and racial diversity—to ensure that programs understand the needs of all families.

• Participate in your State’s budget hearings
  • Learn what budget is allocated for your State Title V program.
  • Testify about families’ needs, why the budget is important to families, what programs or supports are important to families and policy changes that would be valuable to families in your state.

5. Connect with others who partner with Title V

• Talk to others within your F2F, SAO and other family organizations who participate with the Title V staff and ask for additional ideas about ways to be included. Find out from other state F2Fs and SAOs how they participate with their state Title V organization.

6. Share what you learn with other partners and families

• Disseminate information about Title V issues through your listservs, newsletters, websites, on social media and at meetings and conferences or in other ways that you share your information. Share perceptions and feedback.

• Encourage others to work with Title V.

RESOURCES

1. Family Voices resources about Title V: http://www.familyvoices.org/work/title_v
2. MCHB-defined performance measures used by State Title V departments: https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures
3. Title V Information System (provides Title V state program names and contact information): https://mchb.tvisdata.hrsa.gov/
4. Needs Assessment reports for each state: https://mchb.tvisdata.hrsa.gov/Home/StateApplicationOrAnnualReport (Click on your state; on the left-hand side of the pop-up window, select the year you’re looking for. Under “Print Version”, in the “Action” Column, click “View” to open the PDF. In the Table of Contents, click on section II.B. Five Year Needs Assessment Summary” (both the Needs Assessment Update and the 5-Year Summary are available))
5. Family-to-Family Health Information Centers in your state: http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/

Build the partnership! Bring the Family Voice and work together with other families and Title V staff to improve the health of all children!