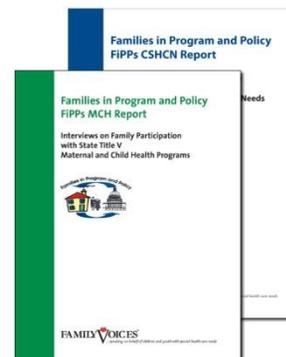




TITLE V TIP SHEET: Lessons Learned from MCH & CSHCN Directors

FIPPS REPORTS

Title V Directors of State Maternal and Child Health (MCH) Programs as well as Children and Youth with Special Health Care Needs (CYSHCN) Programs were interviewed in 2002 by Family Voices to learn more about family involvement in program and policy activities. The results of these interviews were published in two reports on Families in Program and Policy (FiPPs) available on the Family Voices website. Highlights from the reports offer suggestions to help family leaders prepare to successfully partner with Title V.



Download the FiPPs reports:
<http://www.familyvoices.org/work/titlev?id=0012>

BENEFIT OF FAMILY INVOLVEMENT IN TITLE V

Title V Directors rated the benefits of family involvement in their programs. Information on how Title V staff perceive the benefits of family involvement can be a first step in helping family leaders to develop ways to partner with Title V. The chart below indicates the percent of CSHCN Programs rating each of the benefits below as High and Medium value:

1. Increased awareness of family needs (100%)
2. Increased parent/professional communication (96%)
3. Improved policies/responsiveness to family needs (93%)
4. Increased availability of families to participate (86%)
5. Increased responsiveness to federal requirements (84%)
6. Established base for strong coalition for change (84%)
7. Improved understanding of programs (72%)

Tips for Success:

- Programs that contract with family organizations have an easier time finding parents to participate, sustain participation and enhance the value of participation.
- Involved family advocates are able to meet with legislators when services are threatened and to promote ongoing funding.

FAMILY INVOLVEMENT IN COMMITTEES

Involving families in committees, task forces, or other groups is a time-honored method used in public health settings. Title V CSHCN Directors noted the advantages of families serving on broad advisory committees such as MCH/CSHCN or Parent Advisory Committees as well as committees for specific initiatives, such as Newborn Hearing/Screening,

Genetics/Birth Defects, SCHIP, Health Disparities, Medical Home, Early Intervention, Oral Health, Mental Health, Asthma, and many more. Understanding how CSHCN program staff value the committee participation of families can help a family leader prepare to be an active, knowledgeable committee participant.

1. Expressing concerns of families (98%)
2. Developing/reviewing publications and materials (85%)
3. Reviewing/developing policies and procedures (83%)
4. Planning program goals and objectives (83%)
5. Commenting/acting on proposed legislation (66%)

Tips for Success:

- Encourage Title V programs to include more than one family representative on any committee
- Obtain Committee Meeting agendas ahead of time. Review minutes of past meetings if available.
- Gather information from other families about specific issues, such as by reviewing listserv dialogues, obtaining feedback from other family leader staff, compiling data from your family organization tracking system, learning from families at focus groups.
- Learn what makes a handout family-friendly such as language, reading level, reading ease, and cultural competence.

FAMILY INVOLVEMENT IN THE BLOCK GRANT PROCESS

Block Grant applications are submitted by each state and jurisdiction by July 15 of every year. As part of the application process, states/jurisdictions must make the Application/Annual Report available to the public and solicit comments during its development and after it is submitted. This process must be documented in the Block Grant application. Soliciting input can be dynamic (back and forth conversation) or can be passive (submission of comments), but it is an important way families can be engaged in providing feedback on Title V services. Examples of mechanisms that states use to gather input are:

1. Family Council reviews
2. Surveys
3. Facebook postings
4. Public Hearings/Forums
5. Clinic visits
6. Web Forms
7. Outreach to specific stakeholders

The purpose of these public comments is to gather data, information, opinions, and perspectives on who the program is serving; how well the program is meeting their needs; and where additional supports are needed. Family leaders can play an important role in getting the word out about public comment opportunities and in gathering and reporting on family perspectives representing the full diversity of families served.

Tips for Success:

- Ask your state's Title V if they have developed an Executive Summary or other quick reference guide to help families understand the Block Grant application.
- Learn how your state's Title V program solicits public input. Some states collect input year-round by survey. Promote participation in these opportunities for families to provide input through your listserv and in your newsletters.
- Reach out to underserved communities and encourage them or help them to provide input.
- Offer concrete ways that your family organization can solicit input from families.

FAMILY INVOLVEMENT IN ADDRESSING STATE PERFORMANCE MEASURES

A key component of the Block Grant is identifying and tracking state-specific measures. Although these may be similar across state, such as reducing childhood obesity, they are unique to the state and not comparable to other states. The most frequent ‘categories’ of family involvement in specific measures were:

1. Access to health care
2. Morbidity/Mortality
3. Primary/Preventative Health Care
4. Health Screening

Tips for Success:

- Identifying families who have experience with a specific measure will produce more meaningful engagement and feedback. For example, a family who may have experienced Sudden Infant Death Syndrome will have a much better understanding of a morbidity/mortality measure.

SUPPORT FOR FAMILY INVOLVEMENT

It is important for Title V programs to acknowledge and support substantive family involvement. Because family leaders are connected to families, they understand barriers to participation and can help to identify families who can participate as well as advocate to address barriers to participation such as the challenges of engaging diverse families, limits on the time that family members can commit, their ability to travel, and their child care needs. According to the 2002 FiPPs 75% of CSHCN programs and 53% of MCH programs provide stipends or other payment to families for participation; 92% of CSHCN programs and 83% of MCH programs provided travel reimbursement, and 66% of CSHCN programs and 53% of MCH programs helped with child care. In helping families to be involved with Title V, it is imperative for family leaders to advocate for adequate compensation.

Tips for Success:

- Encourage Title V staff to be flexible in meeting dates/times.
- Use video conferencing when possible to eliminate the need for families to participate in-person.
- Help broker a focus group meeting within a diverse community with participation of Title V staff.

RESOURCES

1. Family Voices Family Voices Families in Program and Policy reports: http://www.familyvoices.org/work/title_v?id=0012
2. MCHB-defined performance measures used by State Title V departments: <https://mchdata.hrsa.gov/tvisreports/MeasurementData/NationalMeasures/NationalMeasuresMenu.aspx>
3. Title V Information System (provides Title V state program names and contact information: <https://perf-data.hrsa.gov/MCHB/TVISReports/>
4. Needs Assessment reports for each state: <https://perf-data.hrsa.gov/MCHB/TVISReports/NeedsAssessment.aspx>
5. Family-to-Family Health Information Centers in your state: <http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>
6. Family Voices State Affiliate Organization in your state: <http://www.familyvoices.org>

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