



## First Steps for Family Leaders

### Forming Collaborative Relationships with Your State Title V Program

The mission of the federal Maternal Child Health (MCH) Title V program is to improve the health of all mothers and children, including children with special health care needs (CSHCN). The Maternal and Child Health Bureau administers the provisions of Title V and provides funds through the federal Title V Block Grant to all states and territories.

State Title V MCH Programs are located in State Health Departments; State CSHCN Programs may be located with them or in other human services agencies. Information about each state and territory's programs, including names and contact information for directors, is available on the Title V Information System (TVIS) website at <https://perfddata.hrsa.gov/mchb/mchreports/search/search.asp>.

Below are some 'first steps' family leaders can take to develop or renew partnerships with Title V programs.

1. Familiarize yourself with Title V. A good starting place is to read Getting to Know Title V and other materials on the Family Voices website at <http://www.familyvoices.org/projects/titleV.php>.
2. Read your state's most recent Title V Block Grant - find it at the TVIS website, above.
3. Consider both the general and specific benefits of collaborating with Title V in your state.
4. Attend meetings that your state's Title V MCH and CSHCN Directors and staff attend.
  - ♥ Introduce yourself - ask questions, offer ideas, share information.
  - ♥ Familiarize yourself with their roles and responsibilities.
5. Create opportunities for families to meet your state's MCH & CSHCN Directors and other key staff.
  - ♥ Plan a meeting and create an agenda that includes issues of concern to families.
  - ♥ Propose solutions and work together to improve services.
  - ♥ Talk about the role of families and ways they can be included in the 5-year Needs Assessment and Block Grant Form 13 – the state's yearly report about family involvement.
  - ♥ If you collect data from your work with families, discuss this and offer to share it.
6. Ask to be included on Title V mailing and e-mail lists. Add MCH and CSHCN Directors and key Title V staff to your lists.
7. Disseminate important Title V issues through your listservs, newsletters, websites, and at meetings and conferences, or any other ways you share information. Share insights and feedback.

8. Find out about existing advisory committees and ask to be part of committees that address issues and policies affecting families. When appropriate, bring other family members along – to increase their awareness and to expand the circle of family participation.
9. Talk to others you know who know Title V staff and ask for additional ideas about ways to be included.
10. Share your ideas, interesting information, and new resources with Title V staff in your state.
11. Follow your State budget hearings and find out what's allocated for your State Title V program. When you can, get background information and testify about families' needs and the programs that are – or would be – valuable to them.
12. Build the partnership – working together, families and Title V professionals can improve the health of children!

Go to the Family Voices website at <http://www.familyvoices.org/projects/titleV.php>, for more information and resources. Some of the materials available are listed below.

- ♥ Getting to Know Title V - *A booklet as well as a PowerPoint presentation, with family-friendly background on Title V and the partnership roles families take.*
- ♥ Engaging Families in the Title V Partnership - *A booklet for family leaders and Title V staff to provide background and create opportunities for family participation with Title V.*
- ♥ Family Voices Title V Information System (TVIS) Update - *A one-page information sheet with key points on the extensive site likely to be of interest to family leaders. (Electronically, it's easy to click right to the sites.)*
- ♥ Families in Program and Policy: FiPPs CSHCN and MCH Reports - *Reports of interviews done in 2002 with State Title V staff in MCH and CSHCN Programs about the participation of families.*
- ♥ Title V Toolbox - *A web-based repository of state resources to support family/Title V collaboration.*
- ♥ Title V 5-Year Needs Assessment - *Information about the important assessments states carry out every five years, and which provide the basis for their efforts. Next will occur in 2010.*



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