

Partnerships: Families and Title V Programs

This material was developed by the Family Voices PIC Project, Family Voices at the Federation for Children with Special Needs
1135 Tremont St, Boston, MA 02120

Contact: Lpope@fcsn.org or call
(617) 235-7210 x112



Engaging Families in the Title V Partnership



Accessing Title V Data and Information



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Other Family Voices Title V Materials

- * Families and Title V - Booklet or PowerPoint

- * Action Plan: A Workbook for Families to Participate with States in the Development of Title V Block Grants

- * Partnerships: Families and Title V Programs
 - Engaging Families in the Title V Partnership
 - Accessing Title V Data and Information

- * Partnerships: Families and Title V Programs
 - Family Participation in Title V Block Grant Reviews
 - Suggestions from Parents to Parents
 - Written and Oral Block Grant Review Reports

Notes.....

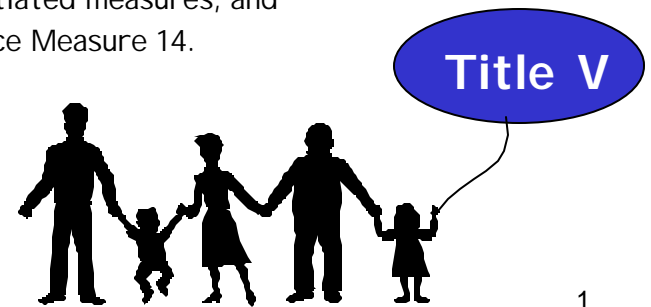
Introduction

This booklet, one of a series, offers families and professionals information, ideas, and strategies to involve and engage families in partnerships with state Title V programs. (See others on the overleaf.) All materials mentioned are available from Family Voices or from the Title V Information System website.

This booklet covers two areas:

1) Lists and briefly discusses eleven activities and strategies that offer families background on Title V and suggest ways they can use and become knowledgeable about Title V and Title V Block Grant resources. It might be especially useful for a parent group to a Title V program.

2) Offers three step-by-step guides to access Title V data. The samples used are for state needs assessment, state negotiated measures, and Performance Measure 14.



Engaging Families in the Title V Partnership

Purposes

- ▶ Help families learn about the role of Title V.
- ▶ Help families learn about Title V Block Grants and data.
- ▶ Highlight opportunities through Title V for families to create and shape quality health care for children, including children with special health care needs.

I. Families and Title V Booklet and PowerPoint presentation. This presentation offers a short overview of Title V. Use the PowerPoint presentation to accompany the booklets and take time to talk a little about each slide. Some are very brief, others will benefit from state-specific information and discussion. It will be helpful to include comments from Title V staff or parents who have participated in Block Grant reviews.

Note: There are two pages that say "sample" - "State Public Health History" and "State History with Families." These can be personalized by inputting information for your state into the slide show. Alternatively, these histories can be discussed when the slides appear.

II. National Performance Measures, general. It might be useful first to identify measures that apply to children and to children with special needs. Then, you might want to print out, from the Title V website, the list of state scores and discuss those for your state. Here, too, Title V staff could add greatly to the discussion. Alternatively, you might want to print out the states in your HRSA/MCHB Region if that would be a better peer group for discussion. Describe how they're measured, progress, problems, and any ways families are involved.

1. Go to <https://performance.hrsa.gov/mchb/mchreports>. You should now be on the Title V Information System (TVIS) home page.

2. Click on: **SEARCH TVIS**.

3. This page offers a variety of choices. Slide down the page and click on **National "Core" Performance and Outcome Measures**.



4. On the National Core Measures page, under Performance Measure - click on "**most recent year available**." (Unless you'd like to see multiple years.)

5. To get information on Performance Measure 14,

- ▶ Slide down the page. Choose a state or region from the drop down menu bar.

- ▶ Leave the **Sort by** and **Results Returned per Screen** option as is, for the moment.

- ▶ Go down the page past **Start Search** to the listing of the eighteen core measures. Click on **Performance Measure 14**.

- ▶ Slide back up the page to **Start Search** and click on it.

6. Voila! You should have the scores for this measure.

ACCESSING TITLE V DATA

STEP-BY-STEP GUIDE

National Performance Measure 14

How to get information on National Performance Measure 14:

These pages focus on states' responses to Performance Measure 14 (the measure on Family Participation with Title V programs in states/territories).

All states/territories are asked to score themselves on this measure - Family Participation in Program and Policy Activities for Children with Special Health Care Needs (CSHCN) programs. This measure is the sum of 6 "program characteristics." The highest score a state/territory can receive is 18. At the moment states devise their own scoring methods. By clicking on "Notes" you may be able to learn what method a particular state used.

Summarized, the program characteristics are: 1) Family members participate on advisory committees and are supported; 2) Financial support is available for parent activities or groups; 3) Family members are involved with the Block Grant process; 4) Family members are involved w/ in-service training; 5) Family members are hired as staff or consultants; 6) Family members of diverse cultures are involved in the above activities.



III. National Performance Measure 14 - Family Participation in Program and Policy Activities in State CSHCN Programs. Especially for this measure, see where your state stands and whether the group agrees with the scores or has any different opinions. Look at your state in comparison to other states nationally or for your Region (or any other grouping that makes sense). Discuss how the scores are calculated and who calculates them. (In some states this is done internally, in others by an outside group of families.) Talk about the 6 components and about the progress and goals your state has set. (Note that WI has a suggested way to score this measure.)

IV. State Performance Measures. Especially important because each state develops their own measures, based on need. (These must be approved by MCHB.) Print out the list for your state. Mention which one(s) specially apply to children/CSHCN. (At least one should address CSHCN.) Say, or have someone from the staff, say how these were chosen, how they're being addressed, progress, problems, and goals. Mention any ways families are involved.

V. Title V Block Grant Application and Report. Describe generally the information states are required to provide to MCHB. Ahead of time, look through your state's most recent report (due yearly in July). You may want to show parents the document at a meeting or copy important sections for the group. For most states it's fairly easy to excerpt pieces that summarize children or children with special health care needs. Another idea is to send this excerpt ahead of time and ask people to come to a meeting having read it. There are many opportunities for discussion: Did people learn things they didn't already know? Is the state doing things that aren't reflected? What are ways the demographic information could be used? The group might also discuss whether an excerpt would be useful for other parents to read.



VI . Title V Block Grant Reviews. Each year states meet with the Maternal and Child Health Bureau and Regional staff to discuss their Block Grant Application and Report, usually in August or September. Typically the meetings occur in the Regional office, but they are sometimes held elsewhere, such as the state itself or, occasionally, by teleconference. Two points of special interest:

1) Since 1997 parents have participated as members of federal Block Grant Review Teams. (Parents receive training beforehand and are selected to review states - other than their own - by the Maternal and Child Health Bureau.)

2) State Title V programs select their own team of participants and sometimes include parents on the state team.

Note: Talk to the Maternal and Child Health Bureau, Division of State and Community Health about additional training and information on the Title V Block Grant.

VII . Needs Assessment. A significant needs assessment is done every 5 years and will be coming up again in 2005. States must collect substantive data to support and describe efforts, needs, and progress. Families might be part of discussions about what information needs to be collected and why. In some states parent organizations are contracted to carry out aspects of the needs assessments.

Note: parents might want to be aware that the information collected typically offers a very in-depth view of the state, its demographic make-up, needs, and resources.

VIII . <https://performance.hrsa.gov/mchb/mchreports>. This is the Title V Information System (TVIS) website devoted to state and national Title V Block Grant information and data. It is updated yearly with new information from states. Everyone can see how states are doing. (This is a culture of accountability and openness, encouraged by the Government Performance and Results Act - GPRA.) You might want to print out a few copies of some parts of the information. In addition to progress on performance measures, reports on various topics can be printed out - children with special health care needs, etc.

Click on the drop down menu and select the state you want. Just below it click on **Start Search**.

5. Voila! This should bring up a listing of the state's 7 - 10 measures! ·

▶ Another option, if you'd like more detailed information on any of these measures, is to go back to Step 3, above or click on **SEARCH**, on the left menu. Then slide down the page and click on **search by detailed description**. On the State "Negotiated" Measure page, click on **State Negotiated Measures: Detailed Description**. On the following page click on the drop down menu and select the state you want. After you click on **Start Search**, you'll have the detailed information about a selected state's negotiated measures.

▶ Another option, if you have a particular topic in mind and want to see which other states are addressing it is to go back to Step 3, above.

a) Slide down the page and click on **search by Keyword**.

b) Slide down to "Keyword" and select from the list of topics, for example, "Family Support Services". In the population menu, for example, select CSHCN. Leave the setting at "59 states and jurisdictions." When you are done specifying your choices, click on **Start Search**.

c) Voila! You should have the states addressing family support for CSHCN.

ACCESSING TITLE V DATA

Step-by-Step Guide

State Negotiated Measures

How to get information on State Negotiated Measures:



These 7-10 measures are important because they are ones states have selected themselves and are likely to represent important issues for a state. (Generally a state is spending considerable time, effort and money on these issues.) The measures must meet certain criteria and be approved by the Maternal and Child Health Bureau. At least one must address children with special health care needs (CSHCN)- though often several do.

1. Go to <https://performance.hrsa.gov/mchb/mchreports>. You should now be on the Title V Information System (TVIS) home page.
2. Click on: **SEARCH** TVIS.
3. This page offers a variety of choices. Slide down the page and click on **State "Negotiated" Performance and Outcome Measures**.
4. The State Negotiated Performance and Outcome Measures page also offers choices. You might want to see both the short and long versions, but click first on **search by state**.

IX. Reports

- Families in Program and Policy Report, 1993
- Family Employment in State Title V Programs, Report 1995.

These projects were carried out by the CAPP Project at the Federation for Children with Special Needs, Boston. They included telephone surveys and a conference and were done to explore family participation and employment with state Title V CSHCN programs. Some information might be useful as baseline, to note progress. Information in the employment report could still be quite useful for planning and discussion. Excerpts will soon be on the Family Voices website: www.FamilyVoices.org

X. 2001/2002 MCH-CSHCN Interviews. Families in Program and Policy (FiPPs). In progress. One hundred and four interviews, with MCH and CSHCN Directors were carried out by Family Voices at the Federation for Children with Special Needs. This information will update and expand upon the CSHCN survey done earlier (above) and will collect baseline information on MCH programs. Reports will be available in Spring, 2003.

XI. Title V Family Toolbox. A variety of material collected during the interviews described above, has become a web-based data repository. Items such as: sample contracts, parent activities, structure of advisory committees, ways to score Performance Measure 14, and much more, are available.

Title V Toolbox 
for family participation

www.familyvoices.org/toolbox



ACCESSING TITLE V DATA

STEP-BY-STEP GUIDES

The Maternal and Child Health (MCH) Title V Information System (TVIS) web site contains a wealth of data from state Title V programs. What follows are 3 step by step guides to get you started on accessing Title V data. There's lots more to discover once you're comfortable with the process. (This guide can be adapted to locate other information.)

State Needs Assessment

How to get information on State Priority Needs:
Every five years states/territories are asked to identify and report on priority needs - important health issues that need to be addressed. These priority needs are in a "needs assessment" report. States/territories are expected to use this data to base and plan their state negotiated measures so these issues can be addressed in future years. (While these measures may be changed or dropped, with permission, typically they remain the same for at least several years.) The most recent needs assessment took place in 1999/2000; the next will occur in 2004/2005.

1. Go to <https://performance.hrsa.gov/mchb/mchreports>. You should now be on the Title V Information System (TVIS) home page.
2. Click on: **SEARCH** TV I S Data.
3. Slide down the page and click on **Program Data**.
4. Under "Priority Needs" click on **State Priority Needs**
5. On the Program Data: State Priority Needs page, slide down and click on the state/territory or region you'd like to view. When you are done making your selections, click on **Start Search**.
6. Voila! You should see the Priority Needs for the state/region you clicked. Note that if you clicked a region, the results will be spread down several pages because each state/territory has 7 - 10. Also note that you can see which population the need relates to - CSHCN, MCH, etc.
 - ▶ If you want to do a search based on a specific keyword, click on **SEARCH**, on the left menu. Then slide down the page and click on **Program Data**. On the next page, click on **State Priority Needs Keyword Search**. Slide down the next page to the "Key Word" section and select from the categories. For example, choose "Quality Assurance." In the "Population" section select "CSHCN." Then click on **Start Search**. You'll generate a list of all states/territories with a measure relating to quality assurance for CSHCN!