Partnering in the Title V Block Grant Process
May 14, 2015

Welcome!

• Phone lines are currently muted, and will be opened later for sharing and Q&A. In order to avoid distracting background noises when the lines are unmuted, please mute your own line now using the mute button on your phone, and unmute to speak during sharing and Q&A time.

• Once connected to audio, take the following step if you do not see a phone icon to the right of your name in the Participants list. This greatly helps us manage the audio for an optimal experience for all:

   ← click the information icon on top right of screen. Click “View details”, and find the unique code to identify yourself in the format of #xxxxx#. Enter this code now; there is no prompt.

Partnering the Title V Block Grant Process

Agenda
1. Importance of Family Involvement - Nora Wells, Family Voices
2. Family leader panel
   - Lisa Maynes, Vermont Family Network
   - Pip Marks, Family Voices of CA
   - Joni Bruce, Oklahoma Family Network
3. Highlighted Resources
   - Diana Autin, SPAN (NJ) – Activities by Core Outcomes
4. Q&A, Discussion, Sharing
   (extending to 4:15pm ET as needed)
Partnering the Title V Block Grant Process

➢ Importance of Family Involvement
   Nora Wells, Executive Director, Family Voices

➢ Resources on working with Title V and the Block Grant
   on the Family Voices website:
   http://www.familyvoices.org/work/title_v

Vermont Family Network

VFN Partnering with Title V
Who are Vermonters?

- State population: 626,630
- Total 255 towns, only 9 of which have populations greater than 10,000
- Caucasian population: 95.2%
- Former refugee population: Since the late 80’s over 6,300 people have resettled in Vermont, most of whom live in Chittenden County.
- CYSHCN: 21,790 children

Who is Vermont Family Network?

- Encompasses over 30 years experience working with families in all areas of support.
- Nearly as many years as Title V partner, though the relationship has experienced many changes due to changes in personnel as well as major organizational changes.
- Low staff turnover.
So what have we done?

1. Monthly MCH Leadership Team Meetings
   - Two way exchange of information
   - Face to face!

2. Annual Review Process
   - Boston
   - Family Reviewer/Connection
   - Details of work done under Title V
3. Needs Assessment

- Dissemination
- Qualitative Interview

4. Health Care Financing Specialist

- Teaming on direct work with families
- Again the two way share opportunity.
Relationship nurturing

- **Mutual respect/value for what each brings to the process**
- Follow through on work/promises
- Listening is as important as speaking
- Relationship is the foundation that level of partnership is built upon

Presenter: Lisa Maynes

[Email and phone number provided]
Partnering in the Title V Block Grant Process

The voice of families
the vision of quality health care
the future for children and youth with special health care needs

Family Voices of California

Statewide collaborative of locally-based parent run centers working to ensure quality health care for children and youth with special health care needs.
What does FVCA do?

- Builds the capacity of parent-run centers throughout CA
- Provides families with the information and support they need to make informed decisions about the health care of their children
- Educates and informs families on how to advocate for improved public and private policies
- Works to increase Family/Professional Partnerships at all levels of decision making

California Title V Block Grant Program

- Partnership between MCAH and DHCS
- CA state mandates for Title V program:
  - Yearly applications for Title V Block Grant funds
  - Statewide Needs Assessment every 5 years
Building Partnerships with the State

Collaborations with:
• Health and Human Services Administrations (HHSA)
• Dept. of Health Care Services
  California Children’s Services (CCS)

FVCA Key Positions on State Committees

• Title V Needs Assessment
• Title V Block Grant Application
• Title V CCS Redesign Advisory Board
Key Stakeholders on State Committees - continued

- Children’s Regional Integrated Services Systems
- Medi-Cal Children’s Advisory Panel
- Parents of C/YSHCN participate on various Statewide Workgroups, Taskforces, Committees

FVCA partnership with Title V

- Respect
- Responsiveness
- Team spirit and commitment
- Partnership with families
- Humor
- Gratitude
Challenges in California

- Changes in Leadership
- Major State Budget Cuts
- Same parent representatives

Initiating partnerships with Title V in your State

- Know your State Title V director and staff
- Write formal letter requesting a meeting
- Emphasize importance of MCH core measure: Family/Professional partnerships at all levels of decision making
- Set agenda for a meeting
- Follow up with thanks and notes
- Stay informed on what is happening with Title V in your state
Key strategies for making partnerships work

- Stay connected throughout the year
- Work together to link family members to committees
- Communicate issues clearly, work on solutions together
- Build trust through transparency
- Invite Title V director and/or staff to participate in F2F activities, events
- Celebrate your teamwork

"We value our partnership with you and are grateful for the many parent participants in the CCS redesign workgroups."

Anastasia Dodson, Assoc. Director for Policy, CA DHCS

Building a cadre of family leaders

- FVCA Project Leadership Program
- 78 family members graduated in 2 years
- Many graduates now sitting on boards, committees, task forces around the state
Building a cadre of family leaders

- Legislative visits and testimonies
- [http://familyvoicesofca.org/node/163](http://familyvoicesofca.org/node/163)
- Training curriculum [http://familyvoicesofca.org/node/3](http://familyvoicesofca.org/node/3)

Thank you!!!

Pip Marks
Family Voices of CA
Manager
pipmarks@familyvoicesofca.org
415-282-7494 EXT. 123
Meaningful Family Involvement in the Title V Process

By strengthening partnerships...
We can have a better system of care!

History of Family Involvement with Title V

• CSHCN relationship $$$
• AMCHP attendance, focus Family Involvement
• Block grant review attendance
• Weathering management change
Current Family Involvement

- General Title V Participation
  - Host Joining Forces: Supporting Family Professional Partnerships Annual Conference
    - Identify seasoned family leaders to attend and provide stipends
  - Host Rural Family Professional Partnerships Leadership Institutes
  - Host site for Houston Medical Transition Conference
  - Oklahoma Health Improvement Plan development and participation in implementation meetings
  - Title V Directors’ Meetings Participation
  - Family-to-Family Support

Title V Block Grant Participation

- Block Grant Needs Assessment Tool Development
- Distribution of Block Grant Needs Assessment
- Focus Groups determining health needs in rural areas
- Development of Block Grant Objectives
- Writing and Editing Portions of Block Grant and Reports
- Attendance at Block Grant Reviews
Current Family Involvement with MCH

- **Family Participation:**
  - Preparing for a Lifetime State Monthly Meeting
  - 3 State Level Breastfeeding Workgroups
  - Post-Partum Depression Work Group
  - Screening and Special Services Advisory Group
    - Includes Genetics and Newborn Screening

- **Support Groups:**
  - Breastfeeding moms in NICU
  - Bereavement support for moms of those who have a stillborn, carrying a child to term, miscarriage, post-NICU, etc.

- MCH new staff site visits promoting partnership with OFN and family leaders

Current Involvement with Medicaid

- **Member Advisory Task Force**
  - To improve the SoonerCare Choice program by receiving input and feedback from members and their families

- **Annual Strategic Planning Meeting**
  - Assure SoonerCare Members Have a Voice
  - Decrease Stigma of Being SoonerCare Members
  - Improve/Develop Relationships

- **Convene Families of SoonerCare Members to Review New Policies/Legislation Being Considered**
  - Unintended Consequences

- **NASHP State Health Policy/Children in the Vanguard**
Recruitment of Families

• Far more difficult than in the past
• Support Parents and others involved in your network
• Ask Partners Who They Know
  • Title V, Medicaid
  • Hospital Staff
  • Early Intervention
  • Schools/State Department of Education
  • DRS
  • DD Council/Partners in Policymaking and YLF Graduates
  • PTI Grantee, D70 Grantee, 360 Center Grantee, Federation of Families, Systems of Care, Disability/Ethic Groups, etc.

MCH PHLI Family Professional Partnerships

Project Tools Developed

• Family Leader Request Form
• Family Leader Orientation Agenda
• Family Speaker Request Form
• Family/Professional Partnerships Sample Conference Planning Committee
• Family/Professional Partnerships Sample Conference Agenda
• Family/Professional Partnerships Sample Conference Evaluation
• Family Opportunity Form
• Family Leader Interest Inventory
Family Involvement in Title V Block Grant Processes

Presentation Date & Length: ____________________________
Location: __________________________________________
Audience: __________________________________________
Approximate number in audience: ______________________
Will computer and projector be available for powerpoint? ________
Appropriate Dress: ___________________________________
Objective: __________________________________________

Contact Information (person requesting speaker)
Name: ____________________________________________
Phone: ____________________________________________
Email: ____________________________________________

Will the contact person meet the speaker and introduce them? ________
Please email this request to: (Family Leader Organization representative)
If you have questions, please call (Family Leader Organization phone)

Family Involvement in Title V Block Grant Processes

Please indicate your interest in participation by marking the column/box.

Leadership Interest

<table>
<thead>
<tr>
<th>I am willing to:</th>
<th>Local level (community)</th>
<th>Regional level (states)</th>
<th>Teacher/WP level (cooperation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be an advocate</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Share your knowledge and experience</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Be an interpreter</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Perform group interview</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Participate in activities</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Promote your organization</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Please note the birthdate(s) of your children/family member(s):

[ ] Male [ ] Female [ ] Other

[ ] 0-4 years old [ ] 5-9 years old [ ] 10-14 years old [ ] Age unknown

Family Involvement in Title V Block Grant Processes
### Potential Leadership Activities

- Outreach to encourage family participation via providers and other family leaders
- Assist in collection of information
- Assist in evaluation of programs
- Assist in information sharing
- Partner as co-trainers
- Serve as members of advisory committees
- Facilitate focus groups
Things to Consider

• Manage impact of changing leaders & responsibility
• Develop a coalition of advocates and divide up agencies, each focusing on one
• Have representation among self-advocates and family groups based on passion
• Be careful to include members of groups that don’t often have opportunities to participate

Thank You!

Joni Bruce
Executive Director
Jonib@ofn.mobi
405-271-5072 or 1-877-871-5072
www.oklahomafamilynetwork.org

Email me if you would like a copy of “Family-Professional Partnerships Toolkit”
Partnering the Title V Block Grant Process

- Resources available for download now

- Resources on the Family Voices website: http://www.familyvoices.org/work/title_v

- SPAN’s Activities by Core Outcomes document
  Diana Autin

**Phone lines will now be unmuted. Please mute your own phone unless speaking.**

- Questions? Comments?

- How are family organizations involved in the Title V Block Grant process in your state?

Before you go! Your feedback is important. Please complete a brief survey about this webinar: https://www.surveymonkey.com/s/NCFPPMay15webinarfb
Thank you!

Your feedback is important!

Before you go please complete a brief survey about this webinar:

https://www.surveymonkey.com/s/NCFPPMay15webinarfb