



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.
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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 children¹

¹ 2009/2010 National Survey of Children with Special Health Care Needs

VFN Partnering with Title V

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.

VFN Partnering with Title V



So what have we done?

1. Monthly MCH Leadership Team Meetings

- Two way exchange of information
- Face to face!

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2. Annual Review Process

- Boston
- Family Reviewer/Connection
- Details of work done under Title V

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3. Needs Assessment

- Dissemination
- Qualitative Interview

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4. Health Care Financing Specialist

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

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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

VFN Partnering with Title V



Presenter: Lisa Maynes

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VFN Partnering with Title V

FAMILY VOICES of California

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*

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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.



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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

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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

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Building Partnerships with the State

Collaborations with:

- Health and Human Services Administrations (HHSA)
- Dept. of Health Care Services
California Children's Services (CCS)



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FVCA Key Positions on State Committees

- Title V Needs Assessment
- Title V Block Grant Application
- Title V CCS Redesign Advisory Board



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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



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FAMILY VOICES
of California

FVCA partnership with Title V

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



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Challenges in California

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



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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

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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

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FAMILY VOICES
of California

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



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Building a cadre of family leaders

- Legislative visits and testimonies
- <http://familyvoicesofca.org/node/163>
- Training curriculum
<http://familyvoicesofca.org/node/3>



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FAMILY  VOICES
of California

THANK YOU!!!

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Meaningful Family Involvement in the Title V Process



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



Family Involvement in Title V Block Grant Processes

History of Family Involvement with Title V

- CSHCN relationship \$\$\$
- AMCHP attendance, focus Family Involvement
- Block grant review attendance
- Weathering management change



Family Involvement in Title V Block Grant Processes

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

Family Involvement in Title V Block Grant Processes

Title V Block Grant Participation



TITLE V MATERNAL AND
CHILD HEALTH SERVICES
BLOCK GRANT TO STATES
PROGRAM

- 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

Family Involvement in Title V Block Grant Processes

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**

Family Involvement in Title V Block Grant Processes



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**

Family Involvement in Title V Block Grant Processes



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.

Family Involvement in Title V Block Grant Processes

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

OEN Family & Professional Partnership
 Family Speaker Request Form

OKLAHOMA

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

I am willing to:	Local level (please check)	Regional level (please check)	State/National level (please check)
Be on a list <u>serve</u>:			
Send/receive information			
Receive surveys			
Review and comment on materials			
Phone Calls:			
Be a caller on a phone-tree alert list			
Be on conference calls			
Participate in web forums:			
Web meetings/committees			
Review materials/policies			
Share resources			
Mentor:			
Become a Mentor			
Request a Mentor			
Be an interpreter:			
for spoken languages (specify)			
for sign language			
Face to face meetings:			
Be part of a focus group			
Serve on a committee/advisory board, participate in a survey			
Receive training in:			
Co-training			
Leadership			
Mentorship			
Specific disability (identify)			
Participate in dissemination activities			
Write, visit, phone, fax, email policy makers			

Please note the birthdate/s of your child/parent/self-advocate:

name name name
 date of birth date of birth date of birth

Family Involvement in Title V Block Grant Processes

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

Family Involvement in Title V Block Grant Processes

Thank You!



Joni Bruce
 Executive Director
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Email me if you would like a copy of "Family-Professional Partnerships Toolkit"

Family Involvement in Title V Block Grant Processes



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!

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