Engagement of Family Leader Organizations in Non-CSHCN Initiatives

March 26, 2015

Welcome!

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- 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:
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Engagement of Family Leader Organizations in Non-CSHCN Initiatives

1. Malia Corde of New Jersey's Statewide Parent Advocacy Network (SPAN)

2. Amy Nienhuis of Family Connection in South Carolina

3. Jane St. John and Susan Bird of Missouri Family to Family

4. Sharing and Q&A
Statewide Parent Advocacy Network

➤ SPAN founded 26+ years ago
   • 1st grant = PTI (US Department of Education)
   • 2nd grant = Family WRAP (NJ Department of Health Title V)
     Includes Family Voices & Statewide Parent to Parent

➤ Improving Pregnancy & Birth Outcomes Projects
   • Title V funded SPAN to develop & facilitate Partners for Prevention of Birth Defects with CDC funding (based on our successful facilitation of Community of Care Consortium for CSHCN)
   • SPAN reached out to Governor’s Council for Prevention of DD to participate on P4P; Council funded project to educate PCPs on effective communication of prevention/health promotion messages to diverse women & provide support to women (recommended activities from Partners for Prevention group)
   • Title V funded SPAN to serve as the Essex County Improving Pregnancy Outcomes project (Community Health Workers)

Creating the PCP Education Program

➤ Established project Leadership Team including representatives of the Governor’s Council for Prevention of DD (funder)

➤ Built on and integrated activities & learning into Partners for Prevention; expanded into Partners for Prevention of BD & DD

➤ Facilitated focus groups with diverse women of childbearing age re:
   – What & how did doctors communicate health promotion/prevention messages
   – Where did they get their health messages
   – What was working, what wasn’t, what would work

➤ Did an environmental scan of research on effective health promotion/prevention messaging & effective practices

➤ Recruited regional Family Resource Specialists to do outreach to identify practices for training, conduct training, provide family support to women referred by PCPs (including current PT staff)

➤ Developed & implemented PCP training (used learnings from Medical Home & screening trainings), provided support to referred women; used evaluations to continuously improve activities
Barriers/Challenges

• Developing own expanded knowledge & expertise about prevention of BD/DD & health promotion

• Developing new relationships with service providers for adults (such as OB-GYNs) & their state organizations

• Recruiting providers to participate when they thought they were already doing a good job of communicating

• Getting other organizations to see SPAN as focused not just on CSHCN & not just on pediatric care

What worked?

✓ Building on what we already knew & what we already knew how to do
  • Partners for Prevention built on COCC for CSHCN
  • Educating Primary Care Providers on Effective Health Promotion Messages for Diverse Women built on:
    - Medical home learning collaboratives for CSHCN
    - Parent-led screening training for primary care providers
    - Bright Futures/IMPACT work with immigrant parents on health promotion
  • Improving Pregnancy Outcomes built on work providing peer-to-peer support to women of CSHCN (P2P, FRSs, etc.)
  • All projects built on our experience & expertise working with & providing support to underserved women

✓ Expanding & establishing new relationships & resources

✓ Building on existing relationships

✓ Asking the intended beneficiaries what would work & engaging them in all phases of project activities
What are the benefits?

For Families

• Will receive services that are more family-centered
  – Accessible
  – User friendly
  – Culturally diverse

• Chance to work with professionals that value families and see them as a “true” partner

For MCH Staff

• Improve and enhance systems of care

• Train MCH staff about what families need
  – Cultural/language issues
  – Family support
  – Resources

• Help guide development and implementation of state’s block grant application across MCH domains

Lessons Learned

• Be led by those who you hope to help

• Ask for help from those who care

• Be open to new learnings, new relationships, new areas of work

• Focus on life course – not just for children, but for families!

• See the connections, connect the dots
Contact Information

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Contracting With Your Title V Bureau

**Amy A. Nienhuis, LISW-CP, MSW**  
Executive Director  
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1.800.578.8750
About Family Connection of SC

Vision
Our vision is to build a supportive environment in South Carolina where children with special healthcare needs can reach their full potential.

Mission
We are a statewide nonprofit organization with the mission to strengthen and encourage families of children with special healthcare needs through parent support.

Family Connection is the:
• State Family Voices affiliate
• State Family-to-Family Health Information Center
• State Parent-to-Parent (P2P USA)

Contracting with your Title V Bureau

• Clear Scope of Services
• Know your costs
• Relationship Building-Trust
Benefits

• Respect between professionals and families
• Cost effective
• Title V receives parental/caregiver input
• Family Centered Care

Barriers/Challenges

• Lack of understanding regarding role/benefit of parental involvement
• Administrative policies/Agency Rules
Lessons Learned/Tips

- Train
- Build trust & relationships at all levels

Successes & Current Status of Program

- New Parent Advisory Council
- Partnership in Professional Development Training by families for professionals
Contact Information

Amy A. Nienhuis, LISW-CP, MSW
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1.800.578.8750
Jane St. John

- Parent of 24 year old son with special healthcare needs
- Individual Advocacy & Family Support Team
- Life Course Network
- Partners in Policymaking Graduate

Susan Bird

- Mother of 5 year old daughter with special health care needs
- Individual Advocacy & Family Support Team
- AMCHP Family Scholar and Family Delegate
Our organization
Missouri Family to Family
UMKC-Institute for Human Development
University Center for Excellence

Core Principles

- Life Course Framework
  - Focus on ALL – the 100%
  - Vision for a good life in the future
  - Importance of life experiences
  - Positive life trajectory
  - Integrated supports & shared responsibility

- Importance of FAMILY
  - Many roles of family members
  - Importance of maintaining family well-being
Life Course Framework

Partnering at ALL Levels
DHSS – Bureau of Special Health Care Needs

- Statewide health care support services for children and adults with special health care needs
- Programs include: Children and Youth with Special Health Care Needs, Healthy Children and Youth, Medically Fragile Adult Waiver, and Adult Brain Injury.
- The Family Partnership – an initiative between UMKC-IHD, UCEDD and DHSS, funded by MCHB Title V Block Grant

Family Partnership

- Formed by Dept. Health/Senior Services, Special Health Care Needs (SHCN)
- Enhances the relationship between SHCN and families served
- Provides peer support and resource information to families
ECCS

Early Childhood Comprehensive System Project
○ Fosters collaborative partnerships
○ Goal - children healthy and ready to enter school
○ Local stakeholder teams in 12 communities
○ Build capacity through increased community awareness, expanded & diversified funding
○ Works closely with Mo. Coordinating Board for Early Childhood to implement Missouri's Early Childhood State Plan

ECCS Organizations & Systems

Organizations
○ Douglass Community Services
○ Daeoc Early Head Start
○ Pemiscot Initiative Network
○ Child Care Aware of Missouri
○ Missouri Valley Community Action Agency

State Systems
○ Coordinating Board for Early Childhood
○ MIECHV (Home Visiting)
○ Dept. of Health & Senior Services (DHSS)
○ Dept. of Mental Health
○ Dept. of Social Services
○ Dept. of Elementary & Secondary Education
○ Head Start Association
○ Office of Administration
ECCS Partnership

• How it all began
• Activities
• Outcomes

Joint Activities

- Collaborated to develop Core Competencies of Family Leadership materials
- Collaborated to develop guide for organizations and systems on including family leaders
- 2 Early Childhood Summits (2012 and 2013)
- Strengthening Families, Navigating Life Family Enrichment Conference (2014)
Outcomes of Partnership

- Increased pool of strong family leaders
  - 2 non-traditional organizations hosted FL series
- At risk and diverse families connected to F2F
- Able to use funding from ECCS to develop and produce *Core Competencies of Family Leadership: A Guide for Families & Professionals*
- Guidance for organizations and systems for including family leaders as PARTNERS
- Shared expertise

Collaborative Family Conference

- Strengthening Families Conference
- Parents of children, youth and young adults with special health care needs and early childhood family leaders
Challenges and Lessons Learned

- Culture of systems
- Varying paradigms
- Communication
- Culture of language
- Target audience
- Achieving outcomes

Other Partners

- **First Steps**
  Missouri’s early intervention system; provides services to families with children aged birth to three with disabilities or developmental delays.

- **Children’s Trust Fund**
  Missouri’s foundation for child abuse prevention.

- **Project Launch**
  Helping all children reach physical, social, emotional, behavior and cognitive milestones.

- **DMH – Division of Developmental Disabilities**
  Statewide support services for children and adults with developmental disabilities.
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**Phone lines will now be unmuted. Please mute your own phone unless speaking.**

• Questions? Comments?

• Do you have an example to share of family leader organization engagement in a Non-CSHCN initiative?

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Thank you!

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