



## *Engagement of Family Leader Organizations in Non-CSHCN Initiatives*

March 26, 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:



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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**



Family Voices  
New Jersey



## Statewide Parent Advocacy Network

- SPAN founded 26+ years ago
  - 1<sup>st</sup> grant = PTI (US Department of Education)
  - 2<sup>nd</sup> 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

***Malia Corde***

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Improving Pregnancy & Birth Outcomes Projects  
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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)

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)



## Contracting with your Title V Bureau

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

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)



## Benefits

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

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)



## Barriers/Challenges

- Lack of understanding regarding role/benefit of parental involvement
- Administrative policies/Agency Rules

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)



## Lessons Learned/Tips

- Train
- Build trust & relationships at all levels

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)



## Successes & Current Status of Program

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

[www.FamilyConnectionSC.org](http://www.FamilyConnectionSC.org)





## Contact Information

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Jane St. John  
Susan Bird

**MISSOURI**  
FAMILY TO FAMILY

## 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

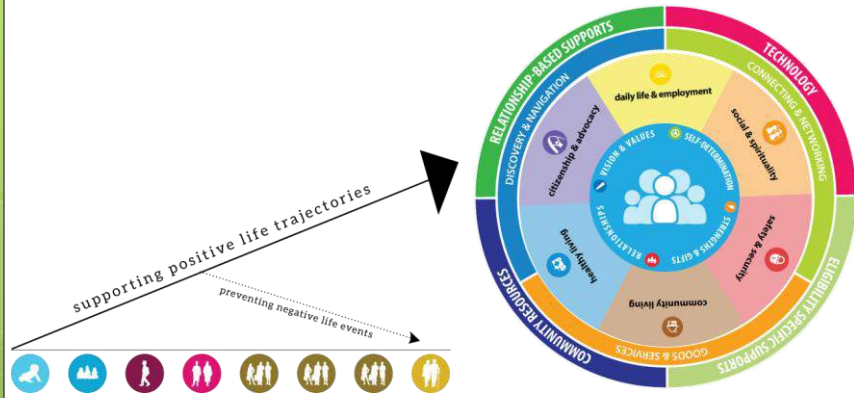
**MISSOURI**  
FAMILY TO FAMILY

**UMKC** Institute for Human Development

## 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



## CHARTING the life course

### Network Overview

National Initiatives	Federal Partners	Network Activities
	<ul style="list-style-type: none"> <li>-Administration on Community Living</li> <li>-NAGDDOS</li> <li>-Human Services Research Institute(HSRI)</li> <li>-AUCD</li> <li>-HHS - Family to Family HCL/MCH</li> <li>-Parent to Parent USA</li> <li>-Family Voices</li> <li>-AACAP</li> <li>-SABE/Autism Self-Advocacy Network</li> <li>-Sling Support Network</li> </ul>	<ul style="list-style-type: none"> <li>• National Community of Practice on Supports to Families (COP)</li> <li>• National Agenda on Supports to Families Winterized Summit</li> <li>• AUCD Supports to Families Special Interest Group</li> <li>• Supporting Individuals and Families Information Systems Project (SIF)</li> <li>• National Core Indicators</li> </ul>
	<b>Missouri Partners</b> <ul style="list-style-type: none"> <li>DMH - Div of Developmental Disabilities</li> <li>32 Family Support Coordinators</li> <li>3 Family Support Coordinator Lead</li> <li>HSF - Special Needs/where there are...</li> <li>4 Family Partners</li> <li>DEIA - First Steps/IV</li> <li>ECCL/HSR/Chv/Project Launch</li> <li>HSAA/SLC</li> </ul>	<b>Network Activities</b> <ul style="list-style-type: none"> <li>• Monthly Reports</li> <li>• Monthly Conference Calls</li> <li>• Face to Face Meetings</li> <li>• Individual TA as needed</li> <li>• Site Visits</li> <li>• Materials development</li> <li>• Toolkits</li> <li>• Professional development</li> </ul>
	<b>Local Partners</b> <ul style="list-style-type: none"> <li>136 Affiliate Organizations</li> <li>12 - Regional Initiatives</li> <li>6 - Project Specific Initiatives</li> <li>75 - Active Affiliates</li> <li>67 - Info Dissemination Affiliates</li> </ul>	<b>Network Activities</b> <ul style="list-style-type: none"> <li>• Monthly Reports</li> <li>• Quarterly Network Conference Calls</li> <li>• Regional Networking</li> <li>• Affiliate Intranet</li> <li>• Direct Referrals</li> <li>• Webinars</li> <li>• Assistance with recruiting and retaining family leaders</li> </ul>
	<b>Family/Self-Advocate Leaders</b> <ul style="list-style-type: none"> <li>942 Family Leaders in Network</li> <li>481 - Trained SOS peer mentors</li> <li>18 - Family Leadership Certificate Series Trained</li> <li>10 - Family Leaders in Certificate Series Training Process</li> </ul>	<b>Network Activities</b> <ul style="list-style-type: none"> <li>• SOS Mentor Manual &amp; Workshop</li> <li>• Core Competencies of Family Leaders: A Guide for Families and Organizations</li> <li>• Family Leadership Certificate Series</li> <li>• Usage to serving on boards and committees</li> <li>• Family Conference</li> </ul>

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

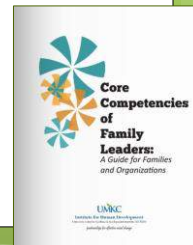


## Joint Activities

- 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)

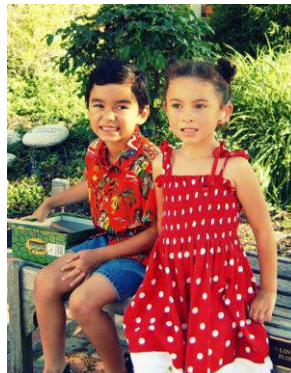
## Outcomes of Partnership

- 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

## Contact Information

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### *Engagement of Family Leader Organizations in Non-CSHCN Initiatives*

\*\*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?

Your feedback is important! Before you go please complete a brief survey about this webinar: <https://www.surveymonkey.com/s/2015WebinarNonCSHCNInitiatives>



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