

Family Leadership and Title V

**Satellite Conference and Live Webcast
Friday, December 2, 2011
12:00 – 1:30 p.m. Central Time**

**Produced by the Alabama Department of Public Health
Video Communications and Distance Learning Division**

Faculty

**Rylin Rodgers, BA
State Coordinator
Family Voices Indiana
Family Discipline Coordinator
Riley Child Development Center
Lebanon, Indiana**

Who Am I?

- **Leader**
 - **Training Director, Family Leadership Coordinator, Riley Child Development Center (LEND)**
 - **State Coordinator, Director, Family Voices Indiana**

Who Am I?

- **Consultant, Early Childhood Comprehensive System, Maternal and Child Health**
- **Mentor, AMCHP Family Scholar**

Who Am I?

- **Family**
 - **Mom to Matthew (14) and Laura (11)**

Who Am I?

- **Married to David, High School Teacher, County Councilman**
- **Drink way too much Diet Coke**

Presenter Disclosure Information

- Rylin Rodgers, BA
- Family Leadership and Title V
- FINANCIAL DISCLOSURE:
 - I have NO financial disclosure
 - I have two children with special health care needs; I have no finances ☺

MCH Roles for Family Leaders for Parent Leaders

- Program Administrators
- Project Leaders
- Policy Makers/Advisors/Consultants
- Program Evaluators
- Members of Task Forces
- Advisory Board Members

MCH Roles for Family Leaders for Parent Leaders

- Leaders of Parent Advocacy Groups
- Grant Reviewers
- Members of Boards of Trustees
- Group Facilitators
- Trainers
- More, Other!!

– Parents as Leaders ©2008, University of Vermont and PACER Center

MCH Leaders at ALL Levels

↑
(family)



Why

- Are you mandated to have family involvement?
- Does funding depend on it?
- Do you see the value of family leadership?
- Are you motivated to impact specific outcomes?

Why

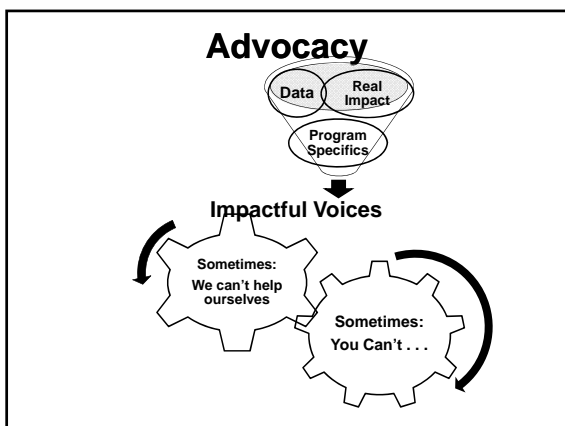
- Is there “value added” you have yet to consider?
- What system change could you see?
- Maximize resources?
- New partnerships?

Benefits of Families as Leaders

- Benefits to Title V
 - Providing parent/individual/consumer perspectives
 - Bringing a sense of reality to ideas and tasks
 - Improving the quality of services and supports

Benefits of Families as Leaders

- Institutional memory
- Ensuring that programs and policies meet the needs of families/individuals
- Cross system and program perspective
- Expanded connections



Maternal and Child Health Changing the World

“Never doubt that a small group of thoughtful, committed citizens can change the world.

Indeed, it is the only thing that ever has.”

Margaret Mead

Maternal and Child Health Changing the World

- 1975: P.L. 94-142.
- 1982: TEFRA, the Tax Equity and Fiscal Responsibility Act
- 2006: Combating Autism Act
- 2011: Combating Autism Act
- Today and beyond: Block Grant Funding, Medicaid, CHIP

Policy Advocacy

- Federal
 - National networks
 - Partners
 - Translating what policy means to families

Policy Advocacy

- **State**
 - **State budgets**
 - **Funding (crisis)**
 - **Programs**
 - **Non-traditional funding partners**

Benefits of Families as Leaders

- **Benefits to Families**
 - **Enhancing skills**
 - **Connection of skills and lived experience**
 - **Validation of expertise**
 - **Expanded resource networks**
 - **Work/life balance**

Involvement vs. Leadership

- **Involvement**
 - **Attending a meeting**
 - **Writing down doctor's order**
 - **Serving on a committee**
 - **Keeping up with legislature**
 - **Advocating for another family**

Involvement vs. Leadership

- **Leadership**
 - **Serving on the board of directors**
 - **Being a partner in deciding care**
 - **Leading a committee**
 - **Speaking to legislators**
 - **Teaching advocacy skills to families**

How We Come to This Place

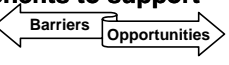
- **Parent**
 - **Did not choose this**
 - **Likely has another job**
 - **Long-term constant in life of child**

How We Come to This Place

- **Professional**
 - **Choose work**
 - **Has many patients/clients**
 - **Relationship is time-limited**

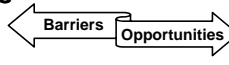
**Institutional Structures:
How Do We Make This Work?**

- Permanent (part- or full-time)
 - Job descriptions and hiring policies and practices that recognize skills and experiences
 - Commitment to development
 - Schedules and benefits to support work/life balance



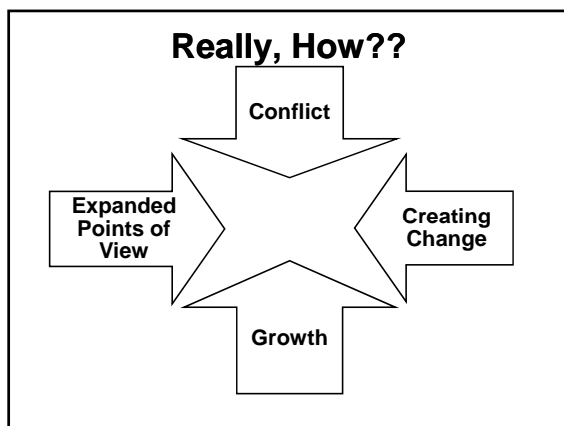
**Institutional Structures:
How Do We Make This Work?**

- Consultants/Committee Members
 - Clear definition of roles, responsibility and commitments
 - Meeting schedules considered
 - Parents should not incur out-of-pocket expenses



**Institutional Structures:
How Do We Make This Work?**

- Parents will know what supports are available
- Parents will have structured opportunities to connect and be mentored

Really, How??

- “I think the greatest barrier to including parents as partners is not supporting their participation... You have to lay the groundwork for it to happen and you have to be OK with what parents say. . . .”

Really, How??

- . . . I think the best example is the schools. They say they want parental involvement, but they really mean to do fundraisers and make copies. If parents actually want to be a meaningful participant, they are threatened.”

How Alabama Works

- Department of Rehabilitation Services
- CSHCN- Local Offices (10 Parents, Statewide)
 - Work around for merit state government system
 - Contract arrangement with non-profit partners

How Alabama Works

- Parent consultant in State Offices (1996)
- Additional roles with Health Department
 - Newborn Screening
- Co-presenters
- Family 2 Family Health Information Center (Family Voices)

How Alabama Works

- Advisory committee
 - Local
 - State level (Saturday)
- Structure
 - Travel
 - Honorarium

How Alabama Works

- Value
- Family lead organizations, growing voice and awareness
- Building leadership skills

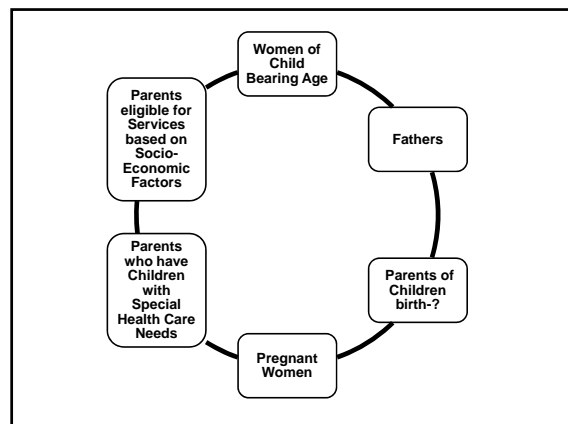
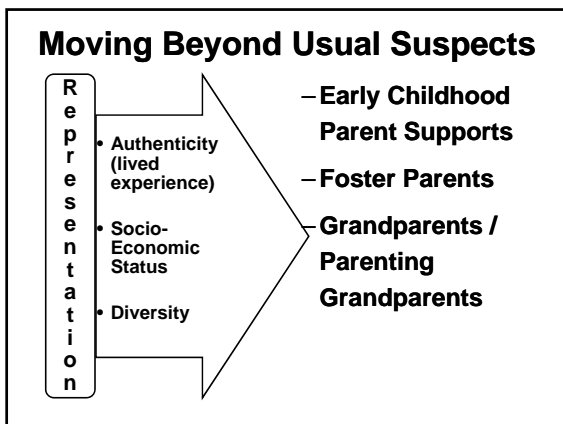
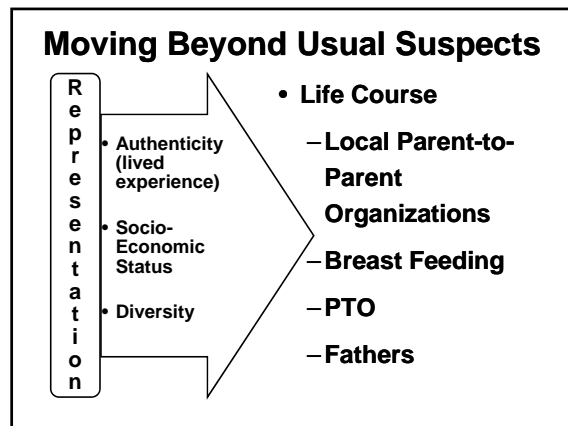
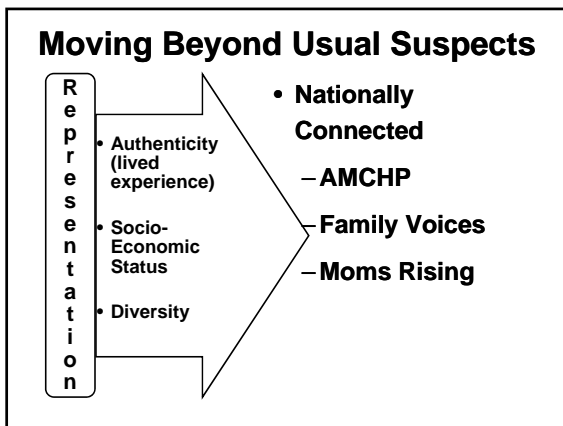
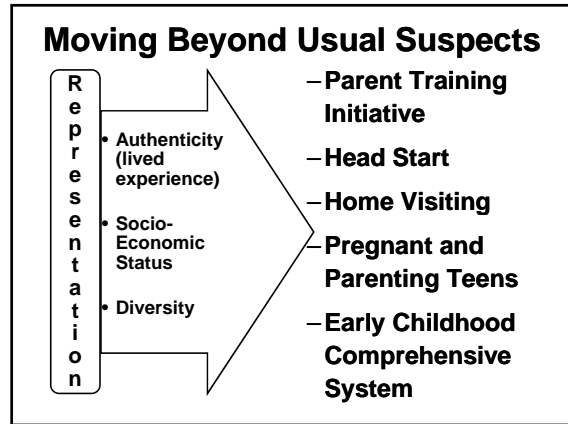
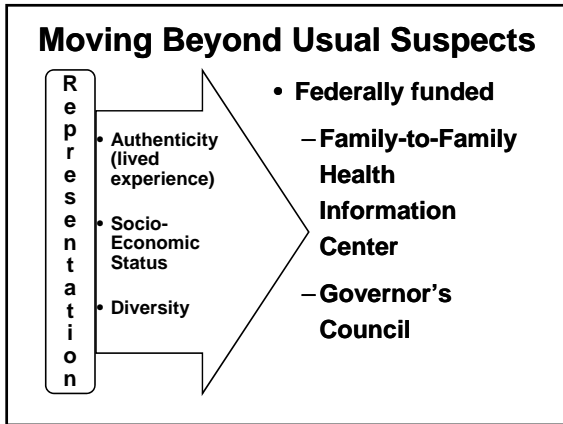
**Leaders . . .
Born? Made? Found?**

Moving Beyond Usual Suspects

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- Authenticity (lived experience)
- Socio-Economic Status
- Diversity

- Disability Specific
 - Down Syndrome Association
 - Autism Society
 - Alexander Graham Bell
 - Hands and Voices
 - Arc
 - United Cerebral Palsy



Who Counts?

- Can you be both a parent representative and an MCH professional?
 - Yes
 - Value added
 - Parent leaders with skills and expertise beyond their lived experience

Who Counts?

- Cultivates connections to family voice
- Ongoing leadership development
- No
 - Role doesn't acknowledge both
 - Until it is time to report family participating

Who Counts?

- Cultivates connections to family voice
- Ongoing leadership development

Who Counts?

- No
 - Role doesn't acknowledge both
 - Until it is time to report family participating
 - Not lived experience
 - Constraints of position limit family voice

MCH Leadership Competencies

- I. Self
 - 1. MCH Knowledge Base/Context
 - 2. Self-reflection
 - 3. Ethics & Professionalism
 - 4. Critical Thinking

MCH Leadership Competencies

- II. Others (Personal Connections)
 - 5. Communication
 - 6. Negotiation and Conflict Resolution
 - 7. Cultural Competency
 - 8. Family-Centered Care

MCH Leadership Competencies

9. Developing Others Through Teaching and Mentoring

10. Interdisciplinary Team Building

III. Wider Community

11. Working with Communities and Systems

12. Policy and Advocacy

- AMCHP 2011

Family Leadership Competencies

Competency 1: Family-Provider Partnerships	
Definition	A relationship where the skills and perspectives of all people in the relationship are used in a way that respects, trusts, values, and coordinates their expertise toward common goals and outcomes.
Why it's important	Family-provider partnership helps families lead their child's care. Family and professional partnerships help meet the needs of all children – at the family, local, and national levels.
Key skills	<ul style="list-style-type: none"> • Develop family-provider partnerships. • Use effective communication strategies with providers

Family Leadership Competencies

Competency Area 2: Cultural Proficiency	
Definition	An ability to interact effectively with people of different cultures. Culture includes the wide range of behaviors, ideas, beliefs, attitudes, values, habits, and traditions of a particular group of people. Families, work groups, neighborhoods, organizations – or the subgroups within them - can all have a unique culture. Individuals are influenced by a variety of cultural backgrounds of which they are a part.
Why it's important	Successful family-provider partnerships recognize the value that each person's unique background, experiences, and traditions contributes.
Key skill	<ul style="list-style-type: none"> • Display cultural proficiency when building provider relationships and working across systems.

Family Leadership Competencies

Competency Area 3: Delivery and Support Systems	
Definition	Programs, formal and informal resources, and organizations that offer services, education, or assistance to help meet specific needs.
Why it's important	All families need outside services to support them. These services are most effective when families know how to find and use services. Service systems are most effective when families help develop, implement, and evaluate them.
Key skills	<ul style="list-style-type: none"> • Find and use needed resources. • Improve coordination and integration of service delivery systems.

Family Leadership Competencies

Competency Area 4: Advocacy	
Definition	Speaking, acting, or writing with or on behalf of a person, an issue, or a need.
Why it's important	Advocacy leads to access and improvement in services. Meaningful change does not happen without advocacy
Key skills	<ul style="list-style-type: none"> • Advocate for emerging evidence-based practices. • Influence systems to strengthen them. • Advocate for effective funding allocation. • Teach children to advocate for themselves

Family Leadership Competencies

- **Competency 1**
 - Family provider partnerships
- **Key skill**
 - Develop partnership relationships

Family Leadership Competencies

Competency Level	Required Knowledge and Behaviors
When you lead in your family you:	<ul style="list-style-type: none"> • Recognize the traits of a provider partnership. • Describe examples of positive family-provider relationships. • Identify your family's needs and strengths and recognize where your family needs support. • Model the traits of a provider partnership and ask your child's providers to help you create a partnership. • See your child as a person first and recognize that his/her diagnosis does not define your child or your family.

Family Leadership Competencies

Competency Level	Required Knowledge and Behaviors
When you lead at the local level you:	<ul style="list-style-type: none"> • Know the people and organizations in your community that serve families and can distinguish effective from ineffective partnership organizations. • Recognize the traits of a provider partnership. • Describe examples of positive family-provider relationships. • Help promote family-provider partnerships to others.

Family Leadership Competencies

Competency Level	Required Knowledge and Behaviors
When you lead at the state or national level you:	<ul style="list-style-type: none"> • Know the people and organizations at the state and national level that serve families and can distinguish effective from ineffective partnership organizations. • Follow the principles of family-provider partnerships as you work with policy-makers and program developers. • Recognize the traits of a provider partnership. • Describe examples of positive family-provider relationships.

- ### Identifying Emerging Leaders
- Meet parents where they are
 - Invite
 - Continuum of options
 - Partners
 - Mentoring

- ### Next
- First steps
 - Access
 - Invite
 - Expand
 - Consider
 - Support
 - Recruit
 - Commit

- ### Next
- Next steps
 - Access
 - Invite
 - Expand
 - Consider
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