Who am I?

Leader

- Training Director, Family Leadership Coordinator, Riley Child Development Center (LEND)
- Coordinator of Care Coordination Program, IU School of Medicine
- State Coordinator, Director, Family Voices Indiana
- Health Care Advocate

Family

- Mom to Matthew (Freshman in College) and Laura (Jr. in High School)
- Bipartisan Marriage to David, High School Teacher, former County Councilman
- Drink way too much caffeine





Families Raising CYSHCN: Canaries in the Coal Mine of American Health Care





7/27/17

Family Leaders Drive Health Policy

1935	1950s	1975	1981	1990	1992	2010	2014	2017
The Social Security Act included provisions for crippled children	Beginning of parent advocacy movement. Focus on winning civil and legal rights for their children. Parents still encouraged to institutionalize their children.	Parents help to pass Education for All Handicapped Children Act which becomes IDEA.	Katie Beckett Waiver started Medicaid Waiver system in response to family advocacy	Families work to pass the Americans with Disabilities Act (ADA) – full participation and independence for people with disabilities.	Family Voices, a national grassroots network of family leaders speaking on behalf of CYSHCN established	Affordable Care Act – people with disabilities and special needs can no longer be excluded from health care coverage	ABLE Act creates tax-free savings accounts for individuals with disabilities - without losing public benefits.	Parents, clinicians and others are essential parts of grassroots engagement around Health Care Policy and other proposals of the current administration

Why Partner with Families?-MCHB

Family/Consumer Partnership: For purposes of the Title V MCH Services Block Grant program and this guidance, as previously noted, family/consumer partnership is defined as:

"The intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level." (Page 33)

Everywhere



Where to Find the Grass

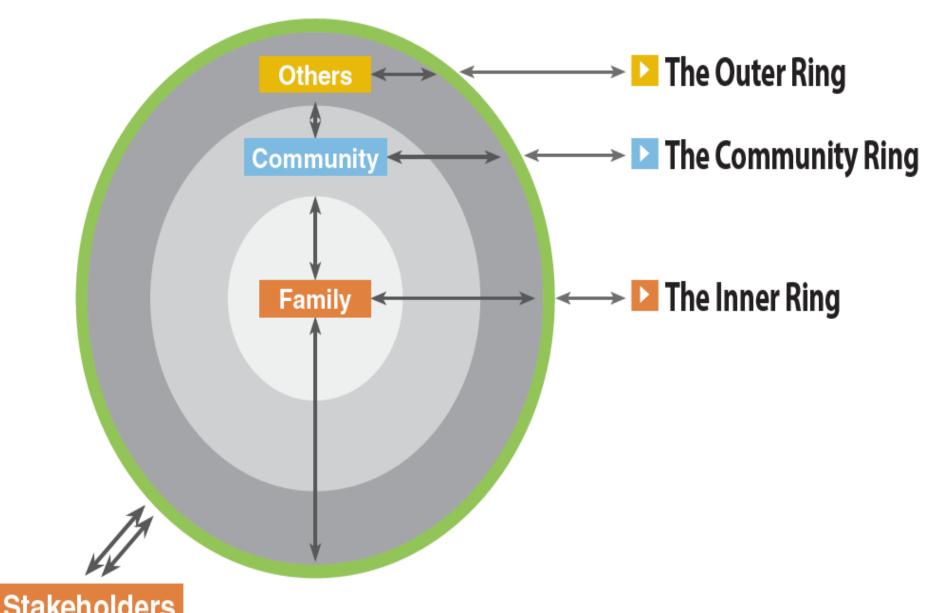
- Family Voices
- Parent to Parent USA
- Parent Training Intuitive
- LEND
- Disability Specific
- Mom's Rising
- Local Support Groups
- Social Media
- Everywhere
 - Grocery
 - Library
 - Waiting rooms
 - Parks

To Find us You May Have to Translate

- DenaliCare
- Centennial Care
- DenaliCare
- Arizona Health Care Cost Containment System (AHCCCS)
- Medi-Cal
- HuskyHealth
- Diamond State Health Plan (Plus)
- MedQuest
- Medical Assistance Program
- Hoosier Healthwise
- IA Health Link
- KanCare Medical Assistance Program
- Bayou Health
- MaineCare
- MassHealth

- ACCESSNebraska
- Centennial Care
- Division of Medical Assistance (DMA)
- SoonerCare
- Healthy Connections
- TennCare
- Green Mountain Care
- Apple Health
- Healthy Families
- BadgerCare
- EqualityCare
- Katie Becket Waiver
- Waiver
- MinnesotaCare
- MO HealthNet

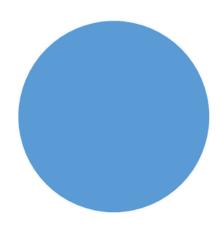
Progression of Leadership





Inner

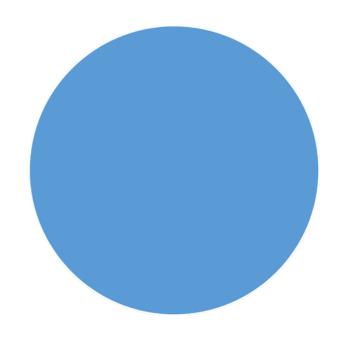
Driving Care for their own Child



- Learn how to coordinate your child's health care needs effectively.
- Connected to local support groups in the area.
- Be informed about legislative issues that will impact your children and families.
- Participate in focus groups

Community

How to pay it forward, smooth the RD



- Write an article about a family success story.
- Contact elected officials about legislative issues that will impact children and families.
- Create a forum to hear from families regarding their overall wellness needs – some of which may include other "systems" (foster care, autism meetings, grief support, etc.).

Outer

I will Change the World

- Recommend policy changes
- Prepare and deliver impactful legislative testimony.
- Write proposed regulations and evaluation measures

Tips for Development

Starting

- Broad and Continuous recruitment
- A synchronous involvement opportunities
- Share Facts about systems
- Post and share opportunities for Input
- Highlight Families Sharing their Voice
- Support Voter Registration and information about voting options

Keeping

- Funding
- Training
 - Fellowships
 - Mentorship
- Professional Pathways

Tips from the trenches

- 1. Consider Risk and Conflicts
- 2. Own words, own story
- 3. Child consent
- 4. Other consent as needed
- 5. Data and Facts too
- 6. Don't Read the Comments

State and National Options

- Family Delegate (AMCHP)
- Block Grant Reviewer
- Mentor (formal and informal)
- LEND Fellows
- Be on the lookout!

Change 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

Never doubt that a small group of thoughtful, committed citizens (Family Leaders) —and massive amounts of Caffeine- can change the world. Indeed, it is the only thing that ever has.

-- Margaret Mead

Edits by Rylin Rodgers