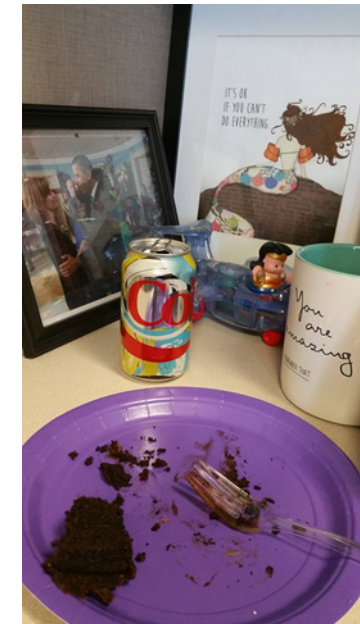


Who am I?

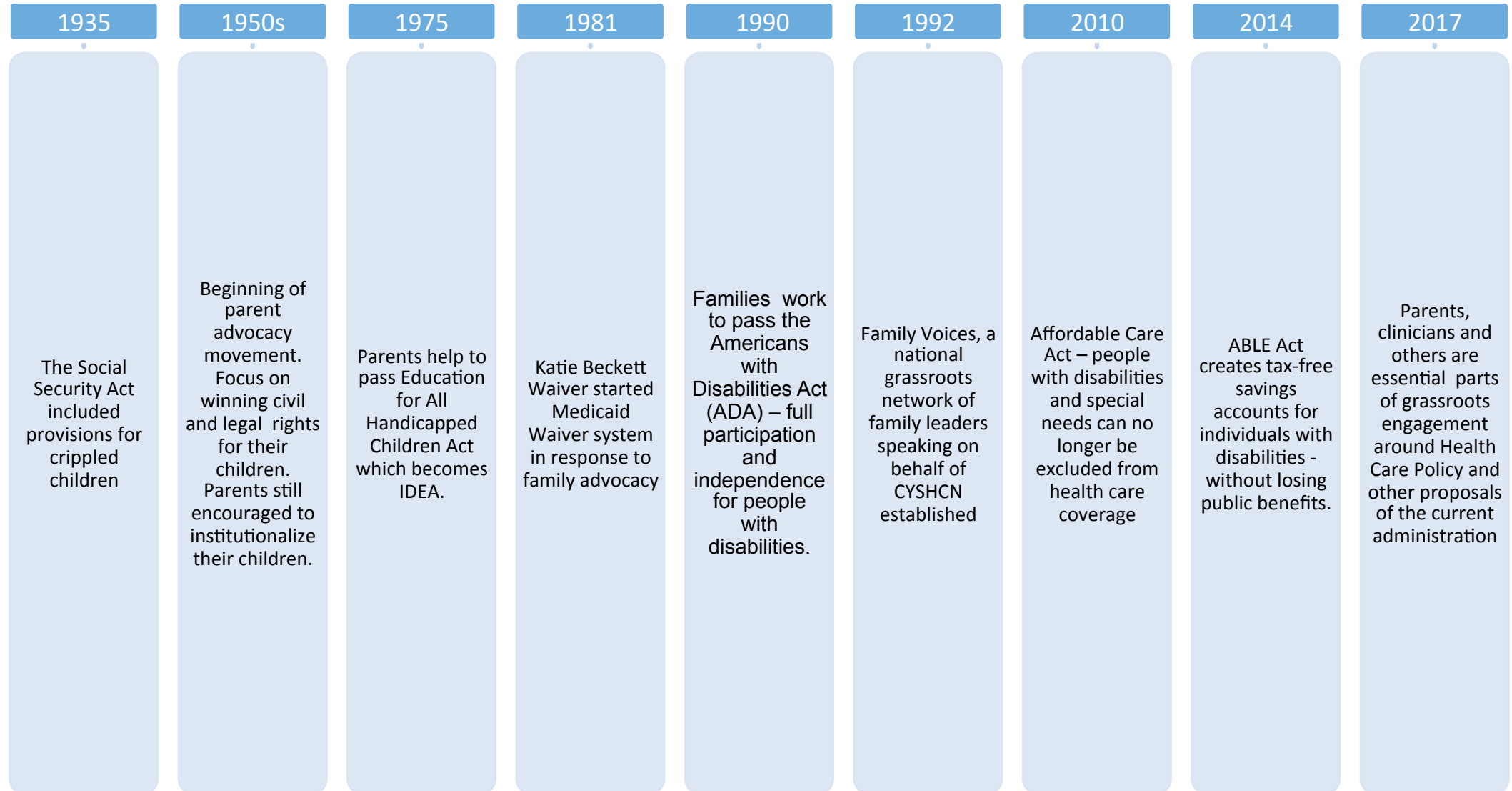
- Leader
 - Training Director, Family Leadership Coordinator, Riley Child Development Center (LEND)
 - Coordinator of Care Coordination Program, IU School of Medicine
 - State Coordinator, Director, Family Voices Indiana
 - Health Care Advocate
- Family
 - Mom to Matthew (Freshman in College) and Laura (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



Family Leaders Drive Health Policy



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



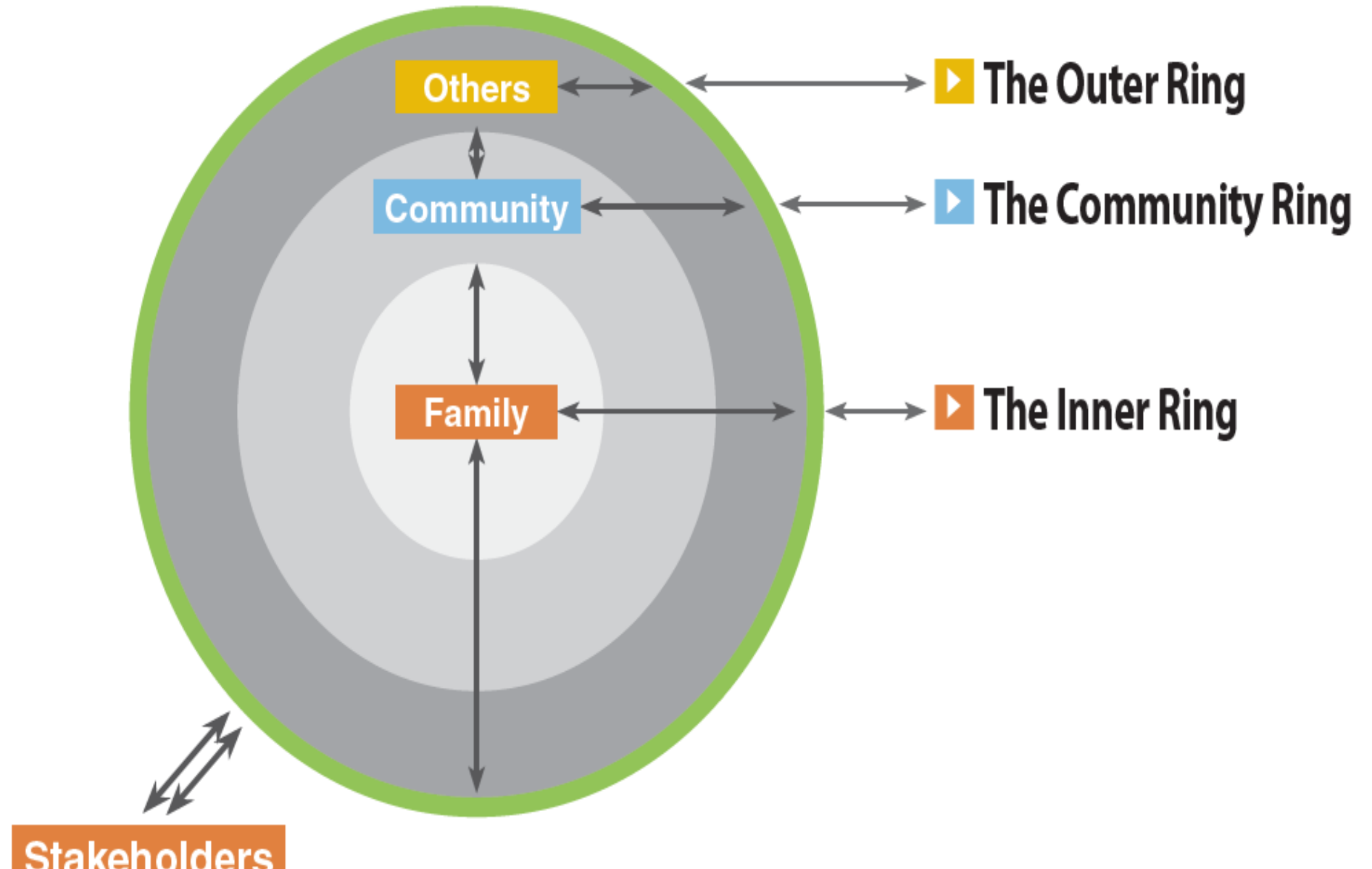
Where to Find the Grass

- 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

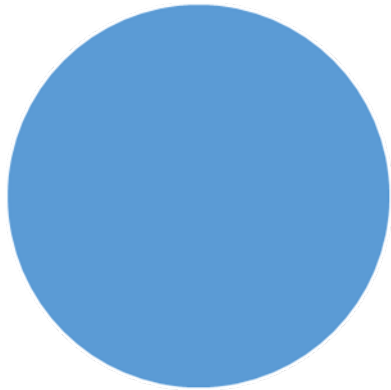
Progression of Leadership





Inner

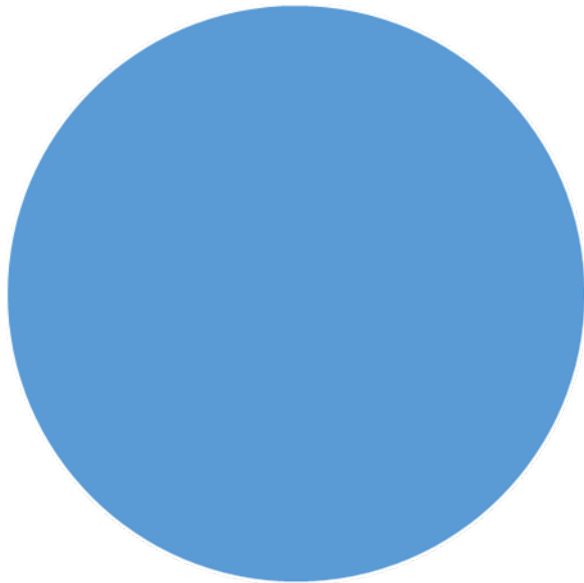
Driving Care for their own Child



- 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