

**Finding Your Voice,
Telling Your Story**

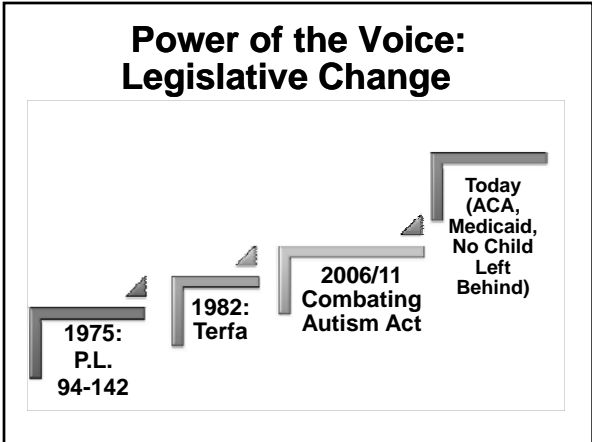
Family-to-Family Health Information
Center's 2012 Partners in Care Summit
Prattville, Alabama
April 16-17, 2012

Faculty

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Training Director
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Family Voices of Indiana

- Agenda: Learning and
Building Together**
- Introduction and Overview
 - The Change Power of Stories
 - Story Telling Tools
 - Speed Storying
 - Networks
 - Impacting Policy
 - Next Steps

- Introductions**
- Your name
 - Number and ages of your children
 - What you want to learn today



- Powerful Stories:
Julie and Katie Beckett**
- Katie spent the first three years of life in a pediatric intensive care unit
 - Her mom Julie pushed for reform and after six years Congress passed TEFRA, the Tax Equity and Fiscal Responsibility Act of 1982
 - Home and community-based waiver program

**Powerful Stories:
Julie and Katie Beckett**

- Allows kids who would be institutionalized to be treated at home by keeping them eligible for Medicaid

**Powerful Stories:
Fran Porter**

- Founded first Parent-to-Parent program in the U.S.
 - Allows parents of children with disabilities to share information and emotional support with others through a one-on-one match

**Powerful Stories:
Rud and Ann Turnbull**

- Co-founded The Beach Center on Disability
 - Permanent unit of the University of Kansas
 - Affiliated with the Schiefelbusch Institute for Life Span Studies and the Department of Special Education

Powerful Stories: Change Makers

- Books
 - *Letters to Sam: A Grandfather's Lessons on Love, Loss, and the Gifts of Life*
 - *Tell It As It Is!* by Charles Parker
 - *The Beauty of Love* by Jorge and Laura Posada
 - *The Boy in the Moon* by Ian Brown

Powerful Stories: Change Makers

- *Gifts 2: How People with Down Syndrome Enrich the World* by Kathryn Lynard Soper

Powerful Stories: Change Makers

- Blogs
 - noahsdad.com
 - lovethatmax.com
 - rachelcoleman.com

Powerful Stories: Change Makers

- **Speakers**
 - Eileen Forlenza, Colorado
 - Janice Fialka, Michigan
 - W.C. Hoecke, South Carolina
 - Kristi Sakal, Oregon
 - Dan Habib, New Hampshire

People First Language

- **Use**
 - People with disabilities
 - People without disabilities
 - People with intellectual disabilities
 - A person who has autism
 - He/she has an intellectual disability
 - People with mental illness

People First Language

- Person who is deaf - hearing impaired
- Accessible bathrooms; reserved parking
- Person who is blind - visually impaired

People First Language

- **Instead of**
 - The Handicapped or disabled
 - Normal people
 - Autistic
 - Has a birth defect, is crippled
 - Crazy
 - The deaf

People First Language

- Handicapped bathrooms, handicapped parking
- The blind

What Do You Call People Who Have Disabilities???

- **Boys, girls, students, Sue's brother, Rosita, a neighbor, customer, teammate, athlete, classmate, children, tourists, blondes, brunettes, individuals, members, leaders, people, Alabamians, friends, or any other would you would use for a person**

Your Story: Picking Pieces to Impact Change

- Beginning
 - Where? When? Who?
- Middle
 - Major issue/conflict
- End
 - Resolution, key theme, impact/ask

Your Story: Picking Pieces to Impact Change

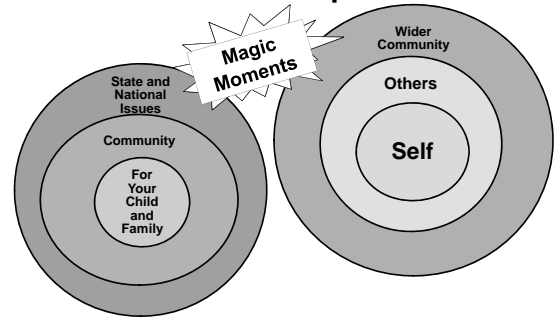
- Simple, clear, and concise
- Relax
- Project
- Eye contact
- Humor
- Crying

Speed Storying: Your Turn

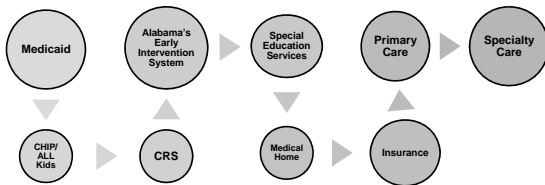
- Groups of 4
- Share 3 minute story
 - Reflect back strength of story

Leadership and Impact

- At all levels and in all places



Systems and Services: Opportunities for Impact



Where Are We?

- Names on dots, dots on map



Connections

- **Building today, changing tomorrow**
- **Group storming to build our connections**

Next Steps

- **Family Voices of Alabama**
 - **About us**
 - **How can we best communicate with/connect with you?**
 - **Goals?**
 - **1 year? 3 years? 5 years?**

Communication and Connection

- **How can we stay connected?**
 - **Listserves**
 - **Emails**
 - **Facebook**
 - **Blog**
 - **Twitter**
 - **Newsletter**