Family Engagement in Policy Decision Making

Julie Beckett
AIM Learning Collaborative Meeting
May 24, 2017

BACKGROUND

Co-Founder of Family voices, Currently on their Board of Directors

Co-chair, FamilY Partnerships Network, American Academy of Pediatrics

Mother of Katie Beckett, the first Medicaid waiver person
IMPORTANCE OF FAMILY PARTNERSHIP

• The family is the center for any child. If the family fails, so will the child
• Planning for access and service delivery begins inside the family structure
• The importance of a comprehensive plan of care
• Identify service structures within the family community

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

• Peer-to-peer support
• Outreach to community leaders, policymakers
• Identify concerns addressed through these centers
• Support community-based programs
POTENTIAL STRATEGIES AND CONSIDERATIONS

• Coverage must be easy to access, flexible, family-centered and comprehensive
• Parents can provide direction and input into who works best for each concern
• Using Bright Futures Guidelines to inform the process for all maternal and child health populations
• Working for the good of the population

Alliance for Innovation on Maternal and Child Health
Learning Collaborative on Improving Quality Access to Care In Maternal and Child Health

Opportunities for Family Engagement in Policy-Making Decisions

Jacqueline Johnson, MPA
Section Chief
Children and Youth with Special Health Care Needs
May 24, 2017
What is Family Engagement

 “The integral 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.”

Why Engage Families

 Families of CYSHCN have a real world experience that governmental and business entities do not have when it comes to making policies and processes more family-centered and culturally competent.
The active involvement of families in the ongoing work of Title V has proved to be an excellent example of how the principle of full partnership can be put into practice.

“Nothing About Us Without Us”
How Families are Engaged

• Provide Technical Assistance
• Block Grant
• Five-Year Needs Assessment
• Focus Groups
• Stakeholder Group
• Advisory Committee Members
• New Born Screening
• Genetics Advisory Committee

• Tennessee Young Child Wellness Council
• Perinatal Advisory Committee
• Children’s Special Services Advisory Committee
• WIC
• MIECHV
• Chronic Disease
• Injury Prevention
Benefits

• Leadership Development
• Opportunities for Employment
• Empowerment – Advocacy
• Connection – Relationship Building
• Family Representative on Special Projects
• Legislative Advocacy
• Family Advisory Councils at Local Children’s Hospitals
• Title V and State Family Voices
• Integration and Implementation of
• Family Input into Team Meetings

Knowledge and Understanding of Family Perspective
• Clear Path to What Works and What Does Not
• CYSHCN Youth Advisory Committee
• Parent 2 Parent Mentoring and Support Network
Challenges

- Communication
- Consistency
- Sustainability
- Family Pool

- Tennessee has committed to fully integrating, engaging, and involving family and youth throughout our processes, i.e., planning, policy development, and implementation.
- One future goal is to include families and youth in monitoring and evaluating our progress.
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