

Family Engagement in Policy Decision Making

Julie Beckett
AIM Learning Collaborative Meeting
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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.

Contact Information

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