

Family Driven, Family Centered and Family Voice and Choice: What's the Difference?

September 13, 2012

Cindy Marshall

Parent and Assistant Director Vermont Federation of
Families for Children's Mental Health

Background

- Concept of family centered care emerged in late 1980s as there was more recognition of the role of families in a child's health and well-being.
- Early models of wraparound promoted families as resources and partners; by the mid-2000s “voice and choice” became a core principle
- In 2003, New Freedom Commission on Mental Health stated mental health care must be consumer and family-driven. A year later SAMHSA asked National Federation of Families to develop a definition.

Where Did These Ideas Come From?

- “Family centered care” is considered an essential part of medical home and is supported by child welfare, American Academy of Pediatrics and early childhood care.
- “Family voice and choice” is one of the 10 principles of wraparound and is used and understood by the many stakeholders in the wraparound process.
- “Family driven” is primarily used in children’s mental health, though it is migrating to other child-serving systems and Peer Support, which is a key component in the new Vermont IFS system of care.

Aren't They Interchangeable?

- The terms are confused because:
 - Children's mental health is becoming more integrated into health (including medical homes), public health and child welfare
 - Each enhances the role of the family
 - Each has emerged from similar values such as partnership, respect, honoring culture of family and communication
- Only family driven defines a role for family organizations and the importance of peer supports
- Outcomes for service system suggests a shift from shared decision making to informed decision making

Why Make the Change?

- Many families raising children with mental health needs are healthy families who are experiencing a particularly stressful challenge.
- Natural parenting skills are not sufficient when a child has mental health needs – when they hear voices, are extremely depressed or anxious, have compulsive behaviors, or are self-abusive.
- Mental health problems that present themselves as “behavior problems” may not be helped by the disciplinary strategies that work with our “typically developing” children. Sometimes using them makes things worse.
- Families coping with additional problems or challenges need even more support to care for and raise children with mental health needs.

A Closer Look at the Comparison Tool

- Each expands the role of the family

	Family Centered	Family Voice and Choice	Family Driven
Role of the Family	Recognizes family has a long-term, ongoing relationship with child and should share decision making	Recognizes family has a long-term, ongoing relationship with child and family preferences should guide the team	Establishes that families have primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation

- Each model expands the role of the family
 - Family centered care articulates family should share decision making
 - Family voice and choice asserts family's preferences should guide care
 - Family driven expands family's role to include both the individual and policy level; allows for informed decision making
- **Only** family driven designates a role for family organizations

	Family Centered	Family Voice and Choice	Family Driven
Guiding Principles	Family-professional partnership	Family voice is intentionally elicited and prioritized	Families make choices for individual children and families and organize for systems transformation
	Child/youth will assume partnership role	Youth voice is respected	Transition to youth-driven as youth becomes ready
	Respect for each other's skills/expertise Communication and information sharing Shared decision making	Family member is encouraged to express own view and self-advocate	Shared decision making and responsibility for outcomes
	Willingness to negotiate	Wraparound team ensures options/choices reflecting family preferences	
	Honors cultural diversity and family traditions	Respects and builds on family's culture and beliefs	Value and celebrate diverse cultures of families, youth and communities
			Focus on removing barriers created by stigma

Highlights

- Guiding principles are mostly shared. The exceptions are:
 - Family voice and choice moves from respect for family's role (found in family centered) to actively encouraging the family to articulate and advocate
 - Family driven asserts informed decision making and includes shared responsibility for outcomes
 - Family driven also focuses on removing barriers created by stigma

	Family Centered	Family Voice and Choice	Family Driven
Key Partnerships	Families	Families	Families
	Youth	Youth	Youth
	Professionals	Wraparound Team Members	Family-led Organizations
			Policy Makers

Important Factors

- All models include family and youth as key partners
- Other partners range from professionals (family-centered) wraparound team members(voice and choice) to family-led organizations along with policy makers (family driven)

Ask Yourself

- What are the outcomes for the family?
 - Increased knowledge, skills, partnerships
 - Greater advocacy skills for self and family
 - Expanded network including other families, policy makers

	Family Centered	Family Voice and Choice	Family Driven
Outcomes for the Family	Parent Satisfaction	Parent Satisfaction	Parent Empowerment
	Inclusion in decision making	Inclusion in decision making that is congruent with values	Increased knowledge, information and capacity to make informed choices
	Reduced stress and worry	Better understanding of options and choices	Reduction in isolation/connection with other families
	Increased adherence to treatment Increased knowledge and skills	Increased knowledge and skills including self-advocacy	Expanded network of families, administrators, policymakers

Consider This:

- What are the outcomes for the system?
 - Practice shift of family-professional partnerships
 - Increased sharing of information/transparency
 - Increased participation of community
 - Increased number of family leaders in policy and evaluation; formal role for family organizations; reduced stigma

	Family Centered	Family Voice and Choice	Family Driven
Outcomes for Service System	Practice shift to include parents in decision making	Practice shift to regularly include family perspective and input	Practice shift to families as primary decision maker
	Increased transparency of information	Team approach	Increased number of family leaders involved in policy and evaluation
	Increased coordination	Increased participation of community stakeholders	Identification and reduction of barriers
			Formal role for family-led organizations
			Greater visibility of needs and reduced stigma

- Key difference:
 - Family centered: family provides input around individual care; professionals are responsible for final decision
 - Family voice and choice: family voice guides decision-making but decisions are made by team
 - Family driven: family makes all decisions and professionals are there to consult and provide expertise
- For families dealing with behavioral health challenges, having families lead the decision-making often determines whether they seek services, stay with services and deem the process a success.

Expanding Parent Roles

Parents as
participants
(sharing
choice)

Parents as
experts
(sharing
knowledge)

Parents as
leaders
(sharing
power)

Which Expands Role of Parent?

- In every model there is an opportunity to expand and strengthen the roles
- Since family centered was first defined, parents have gained progressively more central roles in their child's care and in the teaming process
- Relationship and the primary decisions
- Role of a family partner, providing peer to peer support

From Individual Voice to Collective Voice

Families
expand their
individual role
and impact

Family voice
and choice
leads the *team*
process

Family
organizations
strengthen
collective
family voice

Role of Family Organizations

- Many family organizations encourage family leaders to get involved to improve things for all families.
- Family roles across systems have included families as trainers, evaluators, on governance committees and promoting research.
- However, *only* family driven clearly states that family organizations have a role to provide peer support, create family networks, impact policy making
- Legislation should state family organization, not “a parent”
- SAMHSA defines “family-led organization”

Focus On Reducing Stigma

- Uniquely found only in family-driven principles
- Family driven focuses on reducing stigma both individually and in systems
- Parents whose children have mental health needs often express that they “hope they can help other parents two steps behind them” with access, with information and by increasing awareness, acceptance and support. (Peer Support)

Final Thoughts

- Many of the elements are shared in each model
- Each builds on what works for families
- In many ways the models are a progression
- In *family centered*, the family makes decisions within the personal realm and provides its expertise to professionals who continue to be responsible for professional or clinical decisions.
- In *family voice and choice*, the family is encouraged to lead the decision making but decisions are team based.
- In *family-driven* the family makes the decisions about their involvement and is supported by the team to make informed decisions.

Questions?

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