PARTNERSHIPS WITH FAMILIES IN SYSTEMS OF CARE: STRATEGIES FOR SUCCESS

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Family Driven Care Defined

"Family-driven care means families have a 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. This includes:

a) choosing culturally and linguistically competent supports, services, and providers;

b) setting goals;

c) designing, implementing and evaluating programs;

d) monitoring outcomes; and

e) partnering in funding decisions." [1-3]

http://www.ffcmh.org/family-driven-definition

History of FDC

- Role of families expanded over time[4-5]
  - Causal agents of illness
  - Passive recipients of services
  - Partners in treatment process
  - Service providers
  - Policy makers and advocates
  - Evaluators and researchers

Policy and Legislative Impacts

- Research and Training Center (RTC) (1984)[6]
  - Families as Allies Conference
  - Next Steps meeting
- CASSP Grants (1988)[7]
  - Develop statewide family networks
- Federation of Families for Children's Mental Health (1989)
  - National family-run advocacy organization
- Surgeon General's report on mental health (1999)
- President's New Freedom Commission on Mental Health (2003)
- Patient Protection and Affordable Care Act (2010)

Comprehensive Community Mental Health Services for Children and Their Families Program

- Also known as the Children's Mental Health Initiative (CMHI)

- Funding began in 1992

- Currently funded through the Substance Abuse and Mental Health Services Administration (SAMHSA)

- Purpose: to support communities in the development of systems of care for youth with serious emotional disturbance and their families

☐ The role of families in the CMHI[8]

  ▫ Prior to 1997: "Family-centered"

  ▫ 1997: Families as "partners"

  ▫ 1999: Require family organization

  ▫ 2002: Require Key Family Contact

  ▫ 2005: "Family driven care" and Lead Family Contact

Current Responsibilities of Funded Communities: "The Mandate"[3]

- Ensure that family partnerships are reflected in planning, implementing and evaluating the initiative (i.e., system of care development)
- Administrators and staff share power, resources, authority, and control with families
- Provide financial support to sustain the family/consumer organization as a means to ensure family involvement in the system of care.
- Provide incentives for families who participate in activities related to the development, implementation, evaluation and sustainability of the system of care
- Involve a CMHS-funded Statewide Family Network grantee in the initiative (if one is present in the state)

The Research Study

- Case Studies of System Implementation (CSSI)
  - Goal: Better understand strategies communities use to develop and implement systems of care
  - Five-year national study
  - Examined 6 well-functioning systems of care:
    - Placer County, CA
    - Region 3, Nebraska
    - State of Hawaii
    - Santa Cruz, CA
    - Westchester County, NY
   - Dawn Project (Marion County), IN

The Research Study (cont'd.)

- A qualitative research study that used:
  - In-depth, semi-structured interviews
  - Direct observations
  - Document review
  - Factor ratings exercise
- During data analysis, common theme arose related to the roles of families in system planning and implementation
- Conducted secondary analysis
  - Used same dataset
  - Specifically looked at role of families in system development

Research Questions: Secondary Analysis

1. What structures, processes, and relationships can be identified that are characteristic of family involvement in system level service planning and delivery decisions within established systems of care?

2. What components of a theoretical framework on implementing family driven care, derived from the extant literature, are supported by data from established system of care communities?

Framework
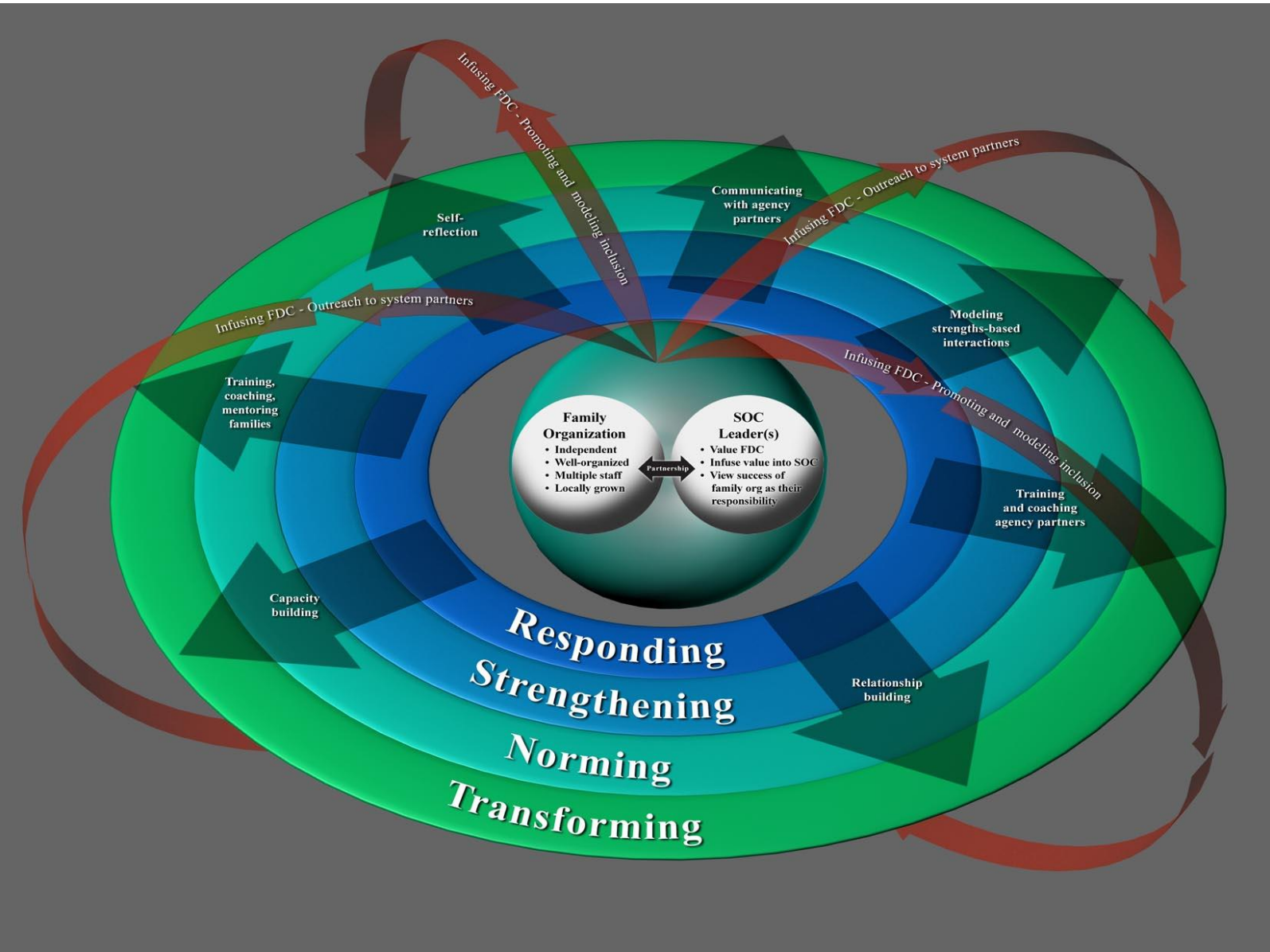
Findings

Four types of key findings characteristic of family involvement at the system level will be described[9]:

- Structures—Specific roles, responsibilities, authorities that define organizational boundaries and enable an organization to perform its functions
- Processes—Methods and procedures for carrying out organizational activities
- Relationships—Trust-based links creating connectedness across people and organizations
- Values—Ideals accepted by individuals or groups

Components of System-Level Family Engagement
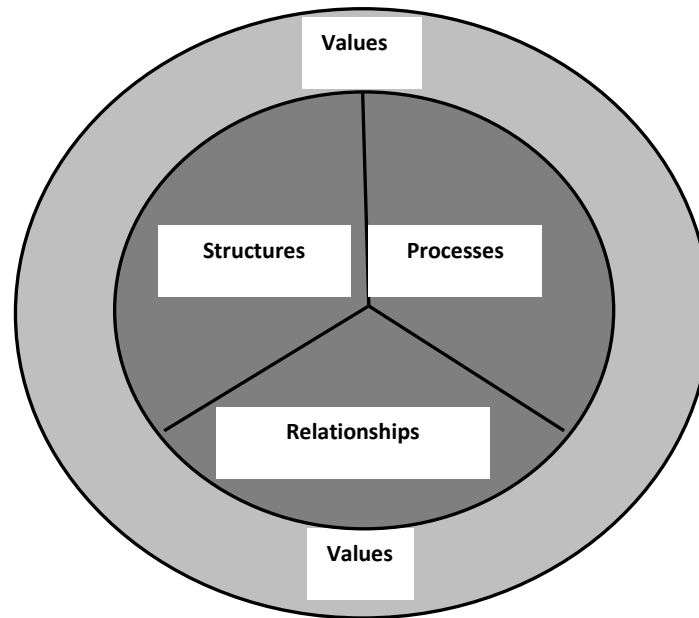
Key Finding: Values

There is a presence of a *shared value* for involvement of families in system level service planning and decision making that results in a *shared commitment* to making this happen.

Shared Values

- SOC Leader(s)
  - Noted that:
    - Inclusion of families is the right thing to do
    - Families are the experts and can contribute meaningfully
    - Success of the family organization is their responsibility
  - Sometimes this value is expressed by only one SOC leader at first (a "champion")
  - How do they walk the talk?

Strategies for Developing a Shared Value for Family Driven Care

- System leaders should regularly articulate the expectation that families be involved in governance and policy decisions and collaborative activities;

- System leaders should model collaboration with families and the family-run organization, ensuring family voice at all levels of governance, even when this means stopping and rescheduling meetings when families are not represented;

- System leaders should regularly engage in self-reflection, exploring new ways in which families can be involved in system-level policy and advocacy efforts

Strategies for Shared Values

- The family-run organization constantly works to infuse FDC into the system
  - Family-run organizations should identify at least one system leader who is a "champion" for family engagement in system-level policy and advocacy and work with them to promote family driven care with system partners;
  - Family-run organizations should work to demonstrate to system partners the benefits of teaming with the family-run organization

Key Finding: Structures

Having family involvement at the system level requires partnership with a family-run organization.

The Family-run Organization

A family organization, <u>with the following characteristics</u>, was found to be critical:

- Engaged
- Locally developed
- Politically autonomous
- Financially independent
- Multiple paid positions
- Equal partner within system

Structures Strategies

- Formal interagency governance and policy boards with authority at the local, state, and federal levels must ensure that their mission and vision statements, bylaws, policies and procedures, logic models, and strategic plans reflect the inclusion of families and clearly articulate their roles and responsibilities;

- Formal interagency governance and policy boards should develop and maintain permanent positions for family members in their membership, and these boards should include multiple and varying family members to gain multiple perspectives

Structures Strategies (cont'd.)

- Family members who participate in governance and policy boards, strategic planning activities, and other system-level policy planning activities should be compensated for their time;

- Family-run organizations should articulate a commitment to policy and advocacy work in their mission statements and develop strategic plans that reflect this mission;

- Family-run organizations should maintain connections with other local, state, and national chapters for support, technical assistance, policy information, and inclusion in policy and advocacy efforts

Key Finding: Processes

System partners engage in activities to create collaborations with and help build capacity of the family-run organization.

Strategies for Strengthening Collaboration

- System Leaders:
  - Should encourage family attendance and participation in governance and policy meetings; support their equal partnership, which includes giving their ideas/suggestions/feedback serious consideration and incorporating their input; assist families to prepare for participating in meetings (e.g., orient them to the board, provide materials of previous and upcoming meeting);
  - Should include families in collaborative activities with other agency partners—activities such as training, grant writing, joint decision-making around funding, cross-agency problem solving, and co-presenting at state and national conference and meetings;
  - Should provide family-run organizations with training and technical assistance in organizational management, grant writing, evaluation/quality assurance activities, working toward 501C3 status in order to support their autonomy and long-term sustainability;
  - Should collaborate on policy change to allow the family-run organization to become part of the provider network and have reimbursable activities

"We were asking families to be a business, kind of. To come in and be an organization. And how do we expect them to do that, unless they just happen to be a business person, but they weren't there. Families didn't get involved to develop an organization. That's not why they were there. We needed the infrastructure, all this stuff, and by golly some of them tried really hard."

Strategies (cont'd.)

- The role of families and the family-run organization:
  - Family-run organizations should work to prepare families for meaningful participation in governance and policy boards and interagency meetings;
  - Family members should attend governance and policy board and interagency meetings and actively participate;
  - Family-run organizations should develop skills needed to run an organization, including training in organizational management, grant writing, evaluation activities, and becoming effective trainers;
  - Family-run organizations should engage in strategic outreach with formal system partners, focusing on developing collaborations, problem solving, and relationship building

"How many people are paying you to make soup and just hold someone's hand?...You have to be a real resource. They're not gonna be paying for us to just be nice people who want to help other nice people."

Key Finding: Relationships

The *process of relationship building* is a critical characteristic of family involvement at the system level.

Relationship Building Strategies

- System stakeholders, in particular system leaders and members of the family-run organization, should model strengths-based interactions with family members and across agency partners. This modeling demonstrates to system partners how to work with families in an expanded role;

- System leaders should include families at every opportunity of system development and implementation;

- System leaders should make a long-term, shared commitment to support the family-run organization (including assisting them in becoming financially and politically autonomous);

- System leaders and family members should acknowledge and prepare for relationship building to be a long-term investment because it takes time to develop relationships, especially due to staff turnover in agencies and family-run organizations

Implications for Family Driven Care

Study findings indicate:

1. Values are foundational

2. A family-run organization is essential for FDC at the systems level

3. Capacity building for new family-run organizations is essential

4. System implementers are responsible for fulfilling the mandate of FDC, *not* family organizations

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Acknowledgements

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