



Actualizing Empowerment: Delivering a Framework for Partnering with Families in System Level Service Planning and Delivery

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24th Annual Children's Mental Health

Research and Policy Conference

Tampa, FL

March 21, 2011



Studying Family Driven Care at the System Level

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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]

Ten Guiding Principles^[1]

1. Families and youth, providers and administrators embrace the concept of **sharing decision-making** and responsibility for outcomes.
2. Families and youth are given **accurate, understandable, and complete information** necessary to set goals and to make informed decisions
3. All children, youth, and families have a **family voice advocating on their behalf** and may appoint them as substitute decision makers at any time.
4. Families and family-run organizations engage in **peer support activities** to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Families and family-run organizations **provide direction for decisions** that impact funding for services, treatments, and supports and advocate for families and youth to have choices.

Ten Guiding Principles^[1]

6. Providers take the initiative to change policy and practice **from provider-driven to family-driven**.
7. Administrators allocate staff, training, support and resources to **make family-driven practice work** at the point where services and supports are delivered to children, youth, and families and where family- and youth-run organizations are funded and sustained.
8. Community **attitude change efforts** focus on removing barriers and discrimination created by stigma.
9. Communities and private agencies embrace, value, and **celebrate the diverse cultures** of their children, youth, and families and work to eliminate mental health disparities.
10. Everyone who connects with children, youth, and families continually advances their own **cultural and linguistic responsiveness** as the population served changes so that the needs of the diverse populations are appropriately addressed

Levels of FDC^[4]

- **Clinical**
 - Staff directly interact with families
 - Direct services and supports
- **Program**
 - Broad programmatic components such as the type of placement or program
- **System**
 - Overall structure, organization, and financing within the system

History of FDC

- Role of families expanded over time^[5-6]
 - Causal agents of illness
 - 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)^[7]
 - Families as Allies Conference
 - Next Steps meeting
- CASSP Grants (1988)^[8]
 - Develop statewide family networks
- Federation of Families for Children's Mental Health (1989)
 - National family-run advocacy organization

Policy and Legislative Impacts (cont'd.)

- CMHI/SAMHSA Grants (1992)^[9]
 - 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

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 Logic of Implementing FDC

- Outcomes argument
 - Improved treatment retention, satisfaction, and levels of active participation in service planning^[10]
 - High engagement by families led to significant improvements in school behavior for their children ^[11]
 - Dearth of studies about family involvement at systems level
- Values argument
 - Regardless of outcomes, family involvement in decision making at any level of the system is simply a right that families should have. ^[12-15]

Problem Statement

- Although mandates of family driven care at all levels have been clearly articulated, there are two issues:
 - No consistent strategy for planners and implementers to carry out this task
 - Planners are challenged with how to make family partnerships a reality

Research Questions

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 factors can be identified that facilitate implementation of the policy mandate of family driven care in established systems of care?
3. What factors can be identified that impede implementation of the policy mandate of family driven care in established systems of care?
4. 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?



Research Methods for Understanding Family Driven Care in the Context of System of Care Implementation

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Qualitative Secondary Analysis (QSA)

- Analysis of pre-existing qualitative data
- Functions^[16]
 - Investigation of new or additional research questions
 - Verification, refutation or refinement
 - Synthesis of research

Advantages

- Cost-effective^[17-20]
- Ensures data sets are used to their full extent^[19,21-27]
- Less burden on participants^[18,23,26,28-30]
- Can serve as a pilot study^[19,22,31]

Challenges

- Lack of context – not having “been there”^[16,21,23-24,27,32-35]
 - Less of a problem in analysis of your own research
- Determining appropriateness of data set^[16]
 - Accessibility
 - Quality
 - Suitability or “fit”
 - Missing data
 - Convergence of research questions
 - Methods

Case Studies of System Implementation (CSSI)

- Five-year national study
- Goal: Better understand strategies communities use to implement systems of care
- Methods
 - Multi-site embedded case study design
 - Site selection criteria
 - Purposive Sampling

CSSI Study

- Team Based Data Collection & Analysis
 - Triangulation of researchers
 - Triangulation of data sources
 - In-depth, semi-structured interviews (209)
 - Direct observations (41)
 - Document review (307)
 - Factor ratings exercise (113)
 - Convergence of stakeholders' perspectives

Secondary Study

- Used data from CSSI study to
 - Explore roles of families in service planning and delivery decisions
 - Investigate elements characteristic of FDC
 - Structures – roles, responsibilities and authorities
 - Processes – methods and procedures
 - Relationships – trust based links
 - Values – ideals accepted by individuals or groups
 - Identify facilitators and impediments to the mandate of FDC
 - Develop a framework
 - Assist communities understanding how FDC is implemented at system level

De-Identification Process

- Replaced Names with Roles
 - Family Member or Advocate – family perspective
 - Youth
 - Service Provider – frontline worker
 - Service Manager – middle management
 - Evaluator
 - Administrator or policy maker – upper management
- Removed instances where respondents referred to themselves in 3rd Person
 - “I reached out to him and he said, ‘Respondent, I can’t help you. I do adults. But I know a top leading child Psychiatrist in the country.’”

Reduction

- Purpose was to select, focus, simplify, and abstract data
- All data was imported into ATLAS.ti
 - Auto-coding:

family/parent involvement,	family/parent empowerment
family/parent driven	family focused
family/parent partner	family voice
family/parent advocate/	Federation of Families
advocacy	family organization
 - Followed by manual document review
 - Spot check showed 1/3 of documents were overlooked

Problems with Auto-Coding

- Too literal
 - “We feel that empowering of families is an important aspect of our system” not captured
- Didn't reflect terminology used
 - Sites used idiosyncratic expressions
 - Families and youth were less likely to use jargon used by professionals

Team-Based Coding

- Codebook
 - Code name
 - Brief (1 line) description
 - Full definition of inclusion criteria
 - Full definition of exclusion criteria
 - Examples
- Coding
 - Completely independent
 - Frequent use of memos

Inter-coder agreement

- Occurred through
 - Use of the codebook
 - Regularly scheduled meetings
 - Use of memos within ATLAS.ti
 - Periodically checking coding agreement
- Intercoder agreement
 - Rose from approximately 60% to 80% during analysis
- More importantly, had complete agreement about themes identified through coding process

Framework Modification

- Original Framework
 - Developed through a literature review
- Second framework
 - Team members developed themes salient to the framework from data set
- Third framework
 - Developed using feedback from focus groups



A Framework for Family Driven Care at the System Level

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Research Questions

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

- 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

Key Finding: Structures

A family organization, with the following characteristics, is critical:

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

Key Finding: Processes

Two distinct sets of processes carried out by:

- All system partners
 - Collaborative activities
 - Training and coaching
 - Family participation in governance meetings
- Family organization
 - Building capacity of families
 - Strategic outreach to system partners

Key Finding: Relationships

The *process of relationship building* is critical

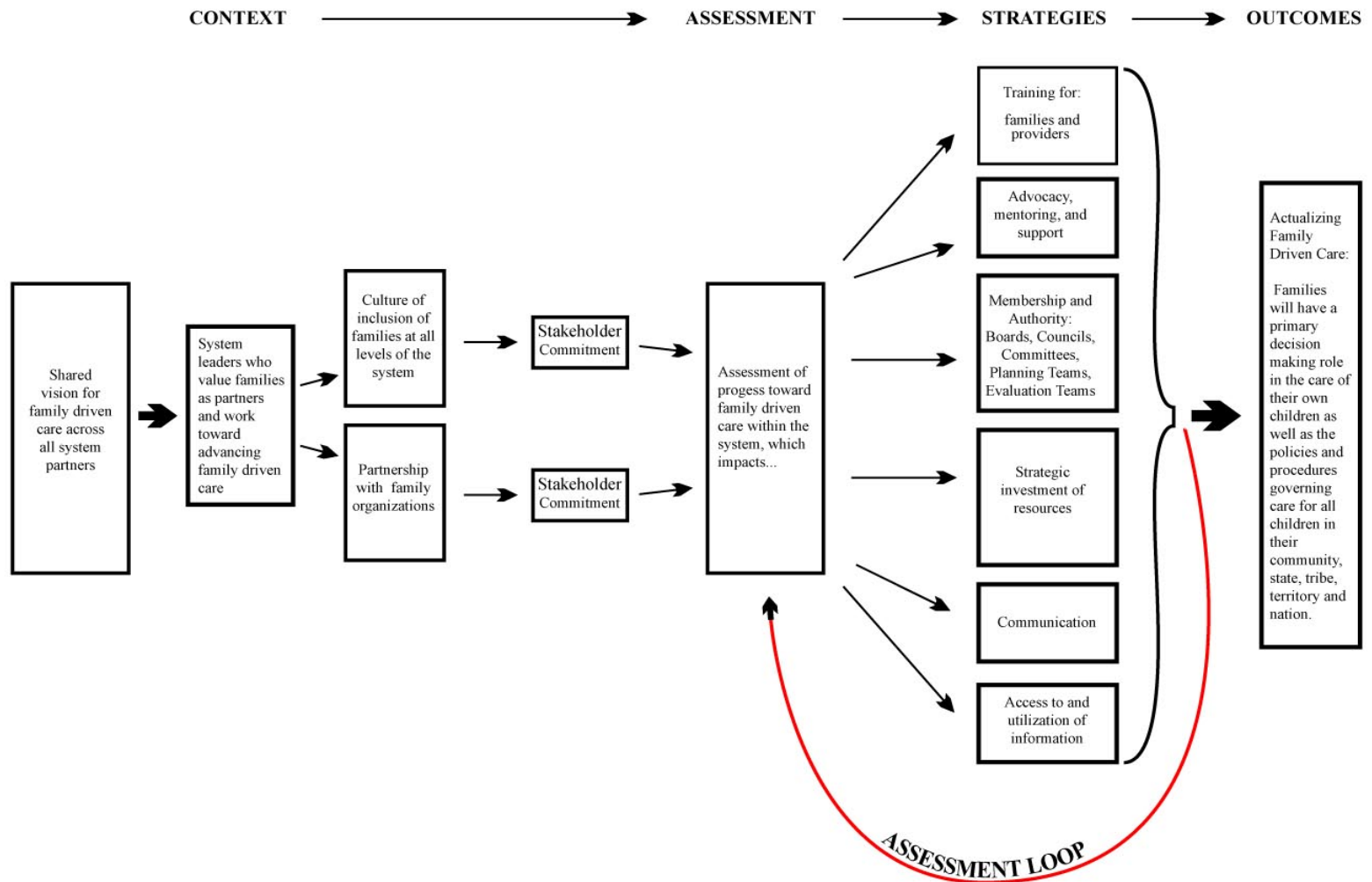
- Modeling strengths based interactions
- Long-term investment
- Relationship building develops trust

Key Finding: Values

Presence of a shared value for involving families at the system level is essential

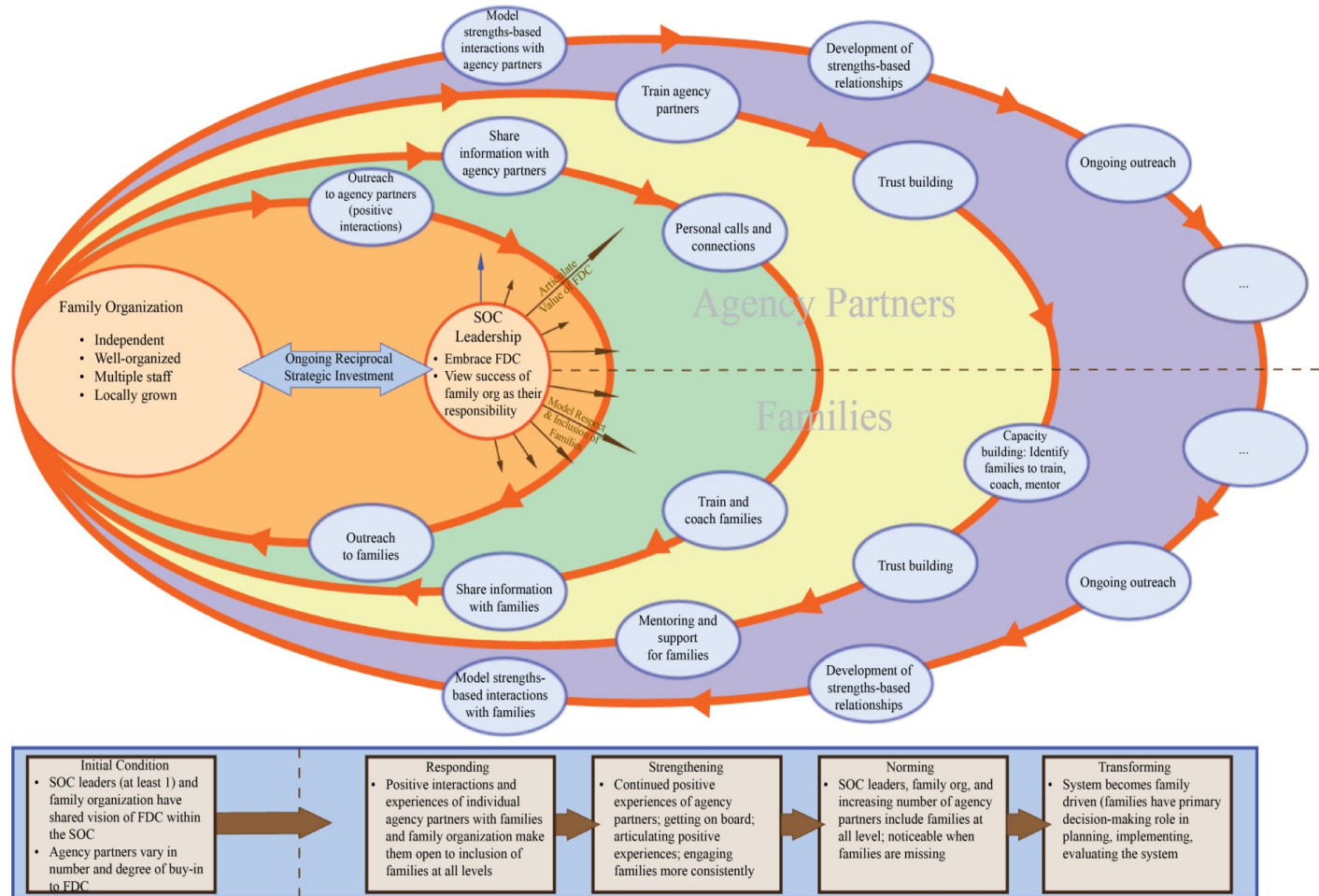
- System leaders actively infuse values
- Family organization is valued as equal partner
- System partners engage in self-reflection

Framework 1

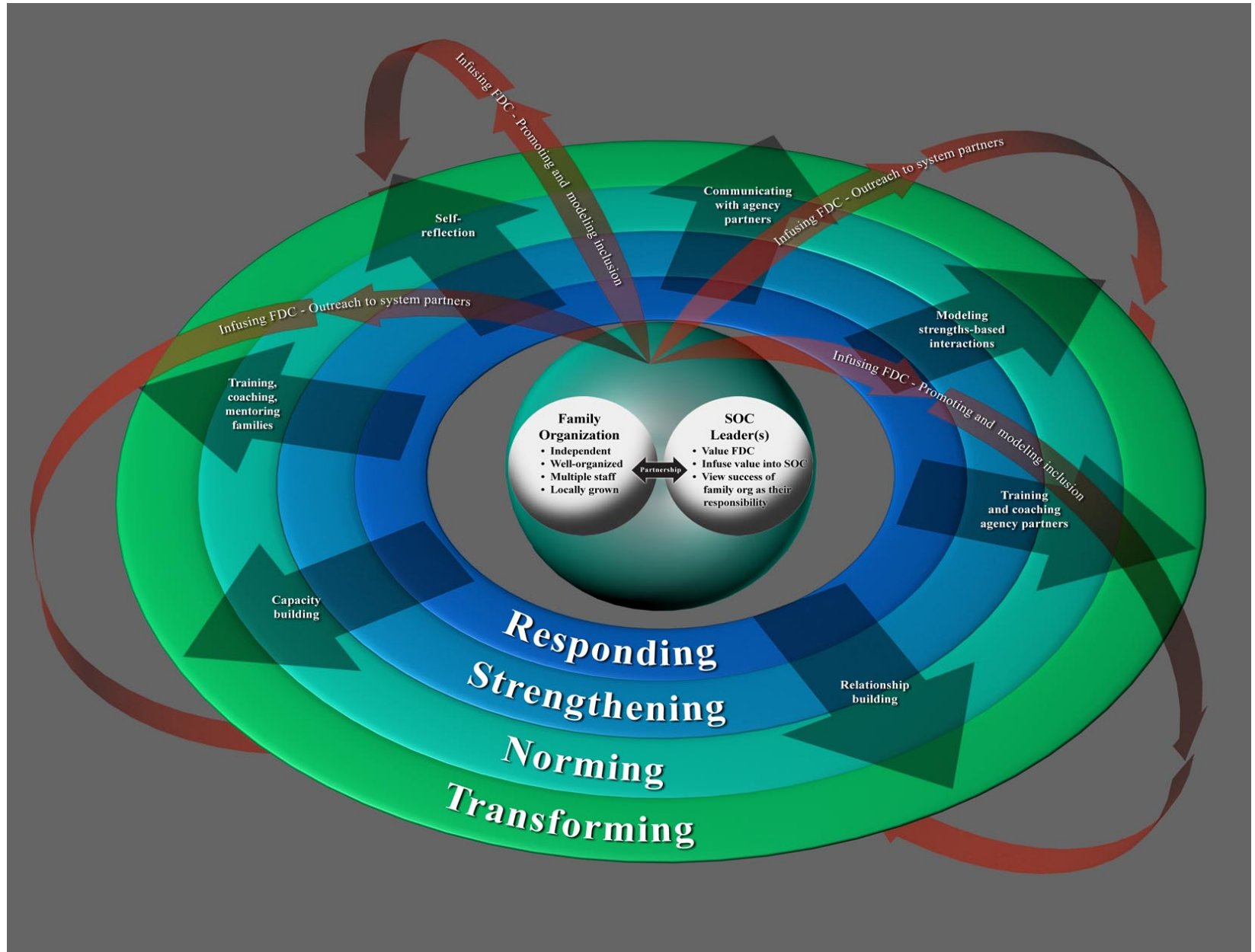


Framework 2

EXPANDING THE ORBIT OF SYSTEM LEVEL FAMILY DRIVEN CARE



Framework 3



The Core

- **Family Organization**
 - Politically independent
 - Financially autonomous (or working towards autonomy)
 - Locally grown
 - Multiple paid staff
 - Leaders know how to run a business and build capacity
- **System of Care Leaders**
 - 1 or more “champions”
 - Articulate value of family-driven care
 - Model respect and inclusion of families
 - Self-reflective
 - See success of family org as system’s responsibility
- **Partnership**
 - Ongoing, reciprocal strategic investment

Infusion of FDC (“Magnetic Force”)

- Ongoing process
 - Articulating value of family involvement in decision-making; modeling inclusion of families
 - Outreach to system partners to encourage inclusion of families

Orbital Rings

- **System activities**
 - Occurs at all levels of the system
 - Training, coaching and mentoring families
 - Communicating with agency partners
 - Modeling strengths-based interactions
 - Training and coaching agency partners
 - Relationship building
 - Capacity building
 - Self-reflection

Developmental Progression

1. Responding—As individual agency partners hear more about FDC, have positive interactions with the family organization and individual families, and observe/experience modeling of strengths-based interactions with families, these agency partners begin to respond by opening themselves to inclusion of families at various levels of the system.
2. Strengthening—Continued positive experiences between traditional agency partners and families and the relationship-building that results creates momentum for FDC

Developmental Progression

3. Norming—Further permeation of family involvement in decision making at all levels of the system. It is noticeable when families are not present; individuals question the lack of family representation and will stop meetings without family representation.
4. Transforming—Reflects a system that has become family driven, with families having a primary decision-making role in planning, implementing, and evaluating the system.

Implications for Family Driven Care

- Structures and processes are necessary but not sufficient
- Values are foundational
- System implementers are responsible for fulfilling the mandate of FDC, not family organizations
- Family organization is essential for FDC at the systems level
- Capacity building for new family organizations is essential

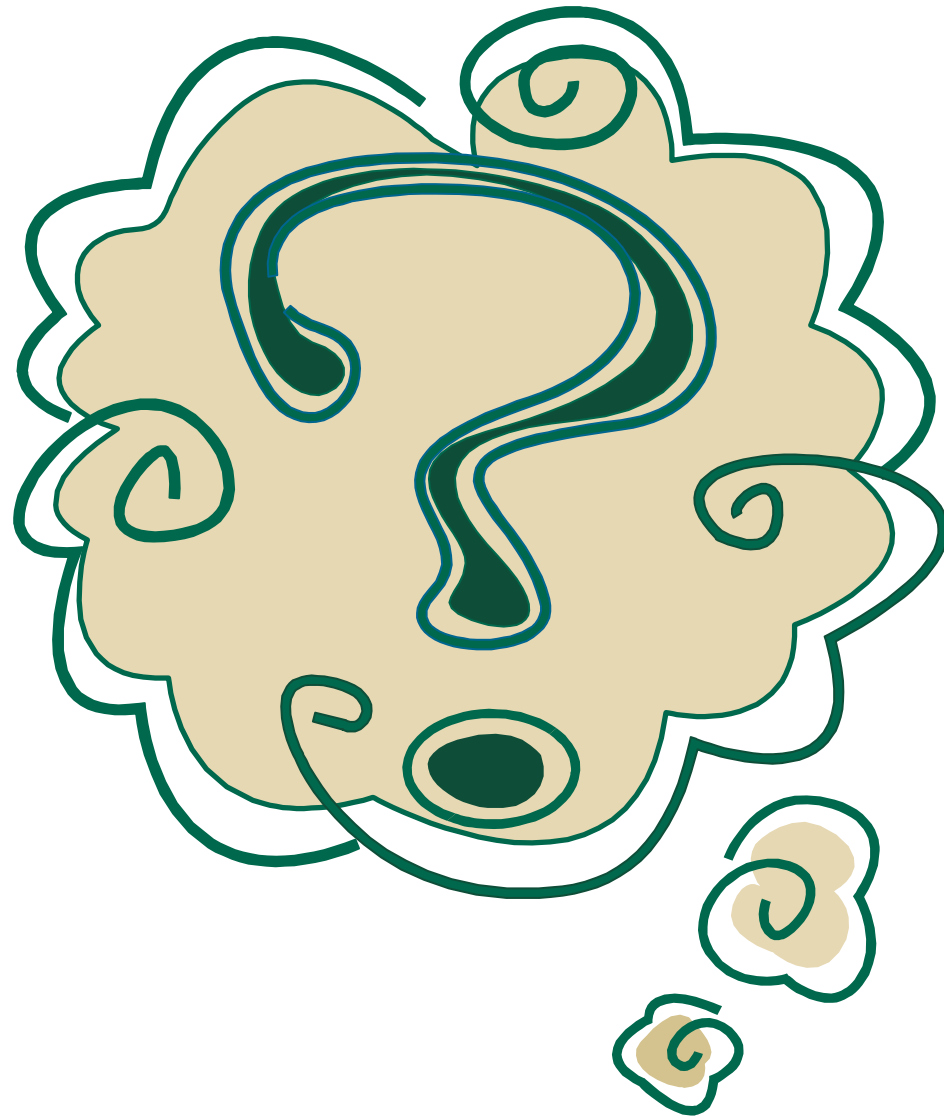


Discussion

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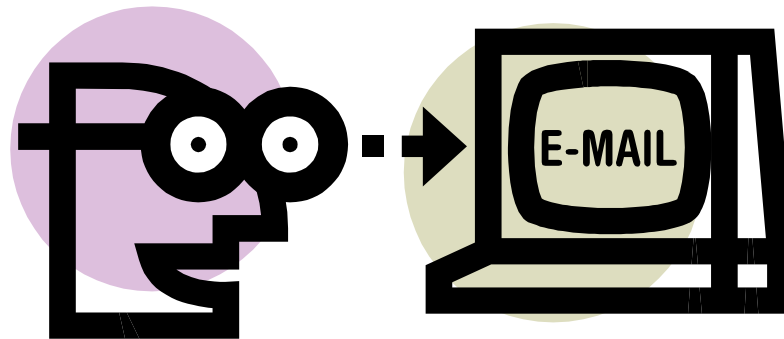
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Acknowledgements

This work was supported by:

- The Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, College of Behavioral and Community Sciences, University of South Florida
- *Case Studies of System Implementation* was jointly funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration under grant number H133B040024 (2004-2009)



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