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

by

Kathleen Ferreira

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Interdisciplinary Education
College of Education
University of South Florida

Major Professor: Albert J. Duchnowski, Ph.D.
Roger Boothroyd, Ph.D.
Robert Dedrick, Ph.D.
Sharon Hodges, Ph.D.
Harold Keller, Ph.D.

Date of Approval:
March 25, 2011

Keywords:
systems of care, family driven care, model, children’s mental health, implementation

Copyright © 2011, Kathleen Ferreira
Dedication

In the memory of my two mothers, Irene Nigro and Brenda Ferreira, the first whose values and early lessons molded me into the adult I've become, and the second who willingly embraced this role to fill the void in my life. To both of my dads, Donald Nigro, Sr. and William Ferreira, for their encouragement of my academic and professional endeavors. To my sister, Ann, an incredible friend and supporter not only during my Ph.D. program but throughout life. To my siblings who periodically checked in to make sure I was still alive during this process: Don, David, Keith, Tim, and Katrina. I love all of you!

But above all, this dissertation is dedicated to my loving husband, Raymond Paul Ferreira, my most ardent supporter and loudest cheerleader, the person who believes in me more than I believe in myself. Thank you for everything.
Acknowledgements

I would like to express my sincerest gratitude to several people who have supported me throughout this educational endeavor. My deepest thanks to Major Professor Albert J. Duchnowski, Ph.D. and “Unofficial Co-Major Professor” Sharon Hodges, Ph.D. (so much work for so little credit!) for their unwavering support and much needed guidance throughout this process. It is not possible to articulate my appreciation.

I would also like to express my appreciation to Dr. Roger Boothroyd, Dr. Robert Dedrick, and Dr. Harold Keller for encouraging me to do my best and always offering kind words of support.

To Dr. Mario Hernandez, not only an incredible Department Chair but a greatly appreciated advocate.

To Emily Koby-Novicki, an invaluable member of our research team. I could never have done this without you.

Finally, many thanks to the system of care communities who showed the courage and willingness to allow a research team from the University of South Florida unlimited access as we attempted to gain a better understanding of how their systems developed.
Table of Contents

List of Tables ..................................................................................................................... vi

List of Figures ................................................................................................................... vii

Abstract ............................................................................................................................ viii

Chapter One: Introduction ...................................................................................................1
  Background and Context..........................................................................................3
  Problem Statement ...................................................................................................5
  Statement of Purpose and Research Questions ........................................................6
  Research Approach ..................................................................................................7
  Rationale and Significance ......................................................................................8
  Assumptions ................................................................................................................9
  Key Terminology .....................................................................................................9

Chapter Two: Literature Review .......................................................................................13
  Systems of Care .....................................................................................................14
    History ......................................................................................................................14
    Related legislation and litigation ...............................................................17
    Bounding a system of care ...........................................................................19
  A Systems Perspective ...........................................................................................20
    General Systems Theory .....................................................................................20
    Systems thinking and practice .....................................................................22
    Systems theory’s alignment with systems of care .....................................23
  Family Driven Care ...............................................................................................26
    Family driven care defined ............................................................................27
    Levels of family driven care ............................................................................30
    History and evolution of families in mental health services ......................31
    Political and legislative impacts ...................................................................34
    The logic of implementing family driven care ..........................................39
      Outcomes argument .......................................................................................40
      Values argument ..............................................................................................42
    Challenges to engaging families ...................................................................44
    Components of successful family driven care ............................................47
    The need for a framework for family driven care ........................................52
  Empirically-Based Frameworks for Family Driven Care ......................................53
    Mental health frameworks ..............................................................................54
    Frameworks from fields beyond mental health ..............................................58
Proposed Framework for Implementing System Level Family Driven Care ......66
Context......................................................................................................................67
  Shared vision..................................................................................................................67
  System leaders ..............................................................................................................67
  Culture of inclusion ........................................................................................................69
  Partnership with family organizations ........................................................................69
  Stakeholder commitment ..............................................................................................69
Assessment ..................................................................................................................69
Strategies ......................................................................................................................70
  Training ..........................................................................................................................70
  Advocacy, mentoring and support ................................................................................70
  Membership and authority ............................................................................................70
  Strategic investment of resources ................................................................................71
  Communication ..............................................................................................................71
  Access to and utilization of information ........................................................................71
Outcomes ....................................................................................................................71

Chapter Three: Methods .............................................................................................73
Introduction ....................................................................................................................73
Research Design............................................................................................................74
  Original study ................................................................................................................74
  Current study ................................................................................................................76
Research Questions .......................................................................................................76
Institutional Review Board (IRB) Approval .....................................................................77
Phase One ......................................................................................................................77
  Data collection ..............................................................................................................77
    Participating sites ........................................................................................................77
    Respondents within each site ....................................................................................78
    Procedures and instrumentation ................................................................................81
      Document review .......................................................................................................81
      Brainstorming exercise: Factor identification and ratings exercise development ....81
      Semi-structured interviews .....................................................................................82
      Direct observations ...................................................................................................82
    Exploring the role of families during original data collection ..................................83
Data Analysis .................................................................................................................84
  Qualitative secondary analysis .....................................................................................84
  Methodological issues in using a secondary data set ..................................................85
  Triangulation .................................................................................................................87
  Organizing a large data set ..........................................................................................88
  Data analysis .................................................................................................................90
    Data reduction ............................................................................................................90
    Codebook development and refinement ..................................................................92
    Coding and identification of themes .......................................................................95
    Reliability and validity .............................................................................................96
Chapter Four: Findings ....................................................................................................103

Question 1: Structures, Processes and Relationships Characteristic of System Level Family Involvement .............................................................................105

Structures .............................................................................................................105

- Membership on system of care governance bodies and interagency committees .................................................................105
- Local development .........................................................................................106
- Political autonomy .........................................................................................107
- Financial independence ................................................................................108
- Partnership ......................................................................................................109
- Multiple paid positions ................................................................................110

Processes ..........................................................................................................110

- Processes carried out by all system stakeholders to support family driven care .................................................................110
  - Collaborative activities ........................................................................110
  - Training and coaching ...........................................................................111
- Family attendance and active participation in governance and committee meetings .................................................................112
- Evaluation activities and dissemination of findings .............................113

Processes carried out by the family organization to support the system of care .....................................................................................114

- Capacity building of families .......................................................................114
- Strategic outreach to system partners ..............................................................115

Relationships ....................................................................................................115

- Modeling of strengths-based interactions with families across agency partners .........................................................................................116
- Long-term investment .....................................................................................117
- Relationship building develops trust ...............................................................119

Values ................................................................................................................121

- System leaders worked actively to infuse these values into the system .................................................................................................122
- The family organization is valued as an equal agency partner within the system ..............................................................................................123
- System partners engage in self-reflection ..............................................................123

The Mandate of Family Driven Care ...................................................................124

The CMHI Cooperative Agreement requirements ........................................125

Question 2: Factors that facilitate the implementation of the policy mandate of family driven care ............................................................126
Lead Family Contact position and family involvement in planning, implementing, and evaluating the system ..........................127
Sharing power and authority ...........................................................................................................................................128
Incentives for families ......................................................................................................................................................128
Provision of financial support for the family organization ..............................................................................................128
Involvement of a CMHS-funded Statewide Family Network grantee ......................................................................................129

Question 3: Factors that impede the implementation of the policy mandate of family driven care ...........................................................129

Lead Family Contact position and family involvement in planning, implementing and evaluating the system ......................129
Shared governance .............................................................................................................................................................130
Family voice ........................................................................................................................................................................130
Adversarial interactions .........................................................................................................................................................131
Sharing of power and authority ...........................................................................................................................................131
Incentives for families ............................................................................................................................................................133
Provision of financial support for the family organization .................................................................................................133
Involvement of a CMHS-funded Statewide Family Network grantee ......................................................................................134

Question 4: Empirically-Based Frameworks ...........................................................................................................................135

Framework 1: Derived from extant literature .........................................................................................................................136
Limitations of Framework 1 .......................................................................................................................................................136
Framework 2: Derived from secondary analysis ....................................................................................................................137
Modifications to Framework 2 .................................................................................................................................................140
Framework 3: Final Framework – Expanding the Orbit of System Level Family Driven Care .................................................................141

Core .........................................................................................................................................................................................143
Family organization .................................................................................................................................................................143
System of care leaders ..............................................................................................................................................................144
Partnership ..................................................................................................................................................................................144
Infusion of FDC (i.e., the “magnetic force”) .............................................................................................................................145
Orbital rings .............................................................................................................................................................................145
System activities ........................................................................................................................................................................145
Developmental progression of family driven care ......................................................................................................................147

Summary ..................................................................................................................................................................................148

Chapter Five: Discussion .............................................................................................................................................................150

Implications for Family Driven Care ........................................................................................................................................150
Structures and processes are necessary but not sufficient ........................................................................................................150
Values are foundational to the inclusion of families .....................................................................................................................152
The presence of a family organization is essential to facilitate family driven care at the system level but not necessarily the individual treatment level ........................................................................................................................................................................153
System implementers, not family organizations, are ultimately responsible for carrying out the policy mandate of family driven care ..............................................................................................................................................154
List of Tables

Table 1. Case Studies of System Implementation Data .................................................... 86
Table 2. Initial Codes ........................................................................................................ 93
List of Figures

Figure 1. Milestones within the Family Movement ......................................................... 37
Figure 2. Developmental Framework for Family Involvement .................................. 55
Figure 3. “Working With Families” Programme Plan: Objectives and Strategies ........ 57
Figure 4. Heuristic Model of Woman-Centered Growth Potential............................ 58
Figure 5. Six Stages of Parent Involvement................................................................. 60
Figure 6. Sample Logic Model for a Districtwide Family Engagement Strategy ......... 62
Figure 7. Five Stages of the Process of Empowerment ............................................. 65
Figure 8. Framework 1: A Literature-based Framework for Implementing Family
Driven Care ............................................................................................... 68
Figure 9. Three-stage Process of Family Driven Care Framework Development........ 135
Figure 10. Framework 2: Expanding the Orbit of System Level Family Driven Care.... 138
Figure 11. Final Framework: Expanding the Orbit of System Level
Family Driven Care .................................................................................... 142
Abstract

The engagement of families of children and adolescents with Serious Emotional Disturbance (SED) as full partners in individual treatment, organizational, and system level decision making has become an important focus for systems of care (SOCs) serving youth with emotional and behavioral challenges. SOCs typically include cross-agency partnerships with mental health, child welfare, juvenile justice, and education for the purpose of providing services and supports for youth with SED who have multi-agency needs. Implementation of a federal mandate requiring family driven care (FDC) within systems of care funded through the Children’s Mental Health Initiative (CMHI) has revealed that most system of care leaders recognize the value of families as full partners in decision making at all levels of the system, strive to have meaningful family involvement, but are challenged by how to successfully engage families in this process.

The purpose of this research study was to explicate more fully the roles of families by examining the structures, processes, and relationships characteristic of family involvement in system level service planning and delivery decisions within established system of care communities and to develop a framework that depicts how SOCs engage families in system level decision making. A qualitative secondary analysis (QSA) was conducted, using data collected through Case Studies of System Implementation, a five-year research study that used a multi-site embedded case study design to examine system of care development. Six well-functioning SOCs throughout the country participated in...
the original study. Team-based data collection from these sites included 307 system documents (e.g., state- and local-level reports; evaluation, grant and budget information; organizational charts), direct observations (41), and semi-structured interviews with key stakeholders (209), as well as stakeholder completion of 113 ratings exercises related to factors critical to system development and implementation. Interviews were conducted with policy makers, administrators, judges, service managers, direct care staff, families, and youth (>18) across all partner agencies within the SOC. Findings from the original study revealed not only information on system development but an emerging theme of the important role of families in planning and implementing the SOC.

A team-based QSA was conducted to more thoroughly examine how families are engaged in system level decision making. Findings reveal the necessity of an engaged, locally developed, autonomous family organization that is regarded as an equal system partner, and at least one system of care leader who promotes FDC. Also present are collaborative activities such as training and coaching, evaluation, and grant writing; and family organization activities such as capacity building of families and strategic outreach to system partners. The SOCs also demonstrate specific relationship-building activities and exhibit a shared value of FDC throughout the system. A framework was developed to depict implementation of FDC based on study findings. The framework was then modified based on data collected during focus groups conducted with Lead Family Contacts, Principal Investigators, and Project Directors from system of care communities currently funded through the CMHI. Research results yield specific structures, processes, relationships, and a foundational shared value for FDC that are present in systems of care that engage families as partners in system level decision making.
Chapter One:

Introduction

“Blamed and shamed.”

Sandra Spencer, 2008, p. xxxiii
Executive Director
National Federation of Families for
Children’s Mental Health

This brief but powerful phrase highlights the long-standing stigma faced by families of children with mental health challenges. Since the 1920s, families have been viewed as possible “causal agents” (Friesen & Stephens, 1998, p. 232) for their children’s emotional and behavioral issues. Over the years, researchers have identified multiple causes for mental disorders and have developed effective treatments, reducing the blame placed on parents (Duchnowski & Kutash, 2007; Friesen & Stephens, 1998). Unfortunately, in many areas of the social service sector and beyond, the stigma surrounding these families persists.

Over the last 20 years there has been an increased emphasis on engaging families in service planning and delivery decisions. This engagement may range from making decisions about the individual treatment of their children to organizational and system level service delivery decisions. There has been a paradigm shift in which families are becoming full partners in decision making at all levels of the mental health service
system. However, such a transformation does not occur without challenges. Strategies to promote more meaningful involvement of families have come in the way of state and federal level policy; a strengthening advocacy movement; and funding for research, training, advocacy, and service system development.

The purpose of this research project was to explicate more fully the roles of families in service planning and delivery decisions through an analysis of the structures, processes, and relationships that support and impede family involvement in system level service planning and delivery decisions in established service systems for children and adolescents with Serious Emotional Disturbance (i.e., systems of care). This study sought to identify the core components and strategies employed by systems of care to successfully engage families as full partners in system level decision making, and to develop a framework that depicts how these processes are carried out. The aim of this research study was to generate new knowledge that would provide insight to the field of children’s mental health regarding how to implement the mandate of family driven care within systems of care. It is expected that findings will aid in system of care planning and implementation.

This chapter will begin with a description of the background and context that were foundational to this research. It will be followed by a statement of the problem, the purpose of the research project, and the research questions that drove the study as well as the research approach that was used. The introduction also includes the rationale and significance of the research project, assumptions that guided this project, and concludes with key terminology used throughout the dissertation.
Background and Context

The statistics are staggering. It is estimated that 20% of children and adolescents within the United States have a diagnosable mental health disorder (Costello, Gordon, Keeler, & Angold, 2001; Friedman, Katz-Leavy, Manderscheid, & Sondheimer, 1996; Kutash, Duchnowski, & Friedman, 2005; Lavigne et al., 1996; Roberts, Attkisson, & Rosenblatt, 1998), and estimates show that between 6 and 10% of these youth have serious emotional disturbance (Friedman et al., 1996, 1999; Kutash et al., 2005), affecting approximately 4.5 to 6.3 million youth. These youth have functional impairments that significantly impact their lives within school, community, and home settings, and many of them have a variety of needs that span service settings such as mental health, special education, child welfare, and juvenile justice.

With the acknowledgement that these children and adolescents have multi-agency needs, federal policy over the last 20 years has supported increased community collaboration and service integration in support of serving these children and adolescents with functional impairments. The impetus for this transformation to collaborative systems is often attributed to Jane Knitzer, whose 1982 monograph, Unclaimed Children highlighted the inadequate and fragmented services of these youth. This was followed by the development of the Children and Adolescent Service System Program (CASSP) principles and Stroul and Friedman’s monograph, A System of Care for Severely Emotionally Disturbed Children and Youth (Day & Roberts, 1991; Stroul & Friedman, 1986). These served to highlight the significant gaps in the children’s mental health service system and offered a framework of collaboration in serving these youth.
Federal reports such as ones from the *Surgeon General’s Conference on Children’s Mental Health* (U.S. Public Health Service, 2000), and the President’s New Freedom Commission on Mental Health (2003) also emphasized the importance of these collaborations. Moreover, federal funding in the way of state block grants and the Substance Abuse and Mental Health Services Administration’s (SAMHSA’s) Comprehensive Community Mental Health Services for Children and Their Families program (also known as the Children’s Mental Health Initiative; CMHI) have provided well over a billion dollars in funding for the development of systems of care for youth with serious emotional disturbance and their families.

One important component of the system of care monograph was the inclusion of a description of the role of parents as partners “in all phases of service delivery including assessment, development of individualized service plans, service provision, service coordination, and evaluation of progress” (Stroul & Friedman, 1986, p. 20). This reflected a shift from parents as causal agents or as passive recipients of services to parents with active roles in service planning and delivery.

Around the time that system of care development was being prioritized by policy makers, researchers, and providers, the importance of families as partners in the process was gaining traction. Funding for research related to family involvement, such as research conducted at the Research and Training Center on Family Support and Children’s Mental Health at Portland State University as well as the development of family support and advocacy organizations such as the National Federation of Families for Children’s Mental Health (FFCMH) provided an avenue for more closely examining the role of families in service planning and delivery. Even Stroul and Friedman’s revised
monograph reflected a shift in thinking (Note: italics have been added for emphasis):

“Families should be involved as full partners in policy making, planning, priority setting, and evaluating the overall system of care for children with emotional disturbances in their communities. Only when parents are active participants in decision making both for their own youngsters and for the overall service system will they be full partners in the system of care” (Stroul & Friedman, 1994, p. 22). The Surgeon General’s report (U.S. Public Health Service, 2000) and the report of the President’s New Freedom Commission on Mental Health (2003) both emphasized the inclusion of families within mental health service planning, with the New Freedom Commission being the first to use the phrase “Family Driven Care” to describe the role of families within the service system.

Funding related to system of care development has also changed significantly. Funders now require that CMHI system of care communities implement family driven care within their systems, in which families, youth, and providers share decision making at all levels of the system and responsibility for outcomes. Funded systems of care employ a full-time family member, a Lead Family Contact, who provides support to families and engages in planning, implementation, and evaluation activities. In addition, these systems of care are also required to have a local family support organization or network.

**Problem Statement**

Federal policy makers and funders have identified as a priority the inclusion of family members as full partners in decision making at all levels of systems that serve children and youth with serious emotional disturbance and their families. In fact, communities funded through the CMHI are required to demonstrate that families are
partners in the planning, implementation, and evaluation of the system. Although these mandates have been clearly articulated, there is no consistent strategy for planners and implementers to carry out this task, and they are challenged with how to make family partnerships a reality.

**Statement of Purpose and Research Questions**

The purpose of this research project was to explicate more fully the roles of families in service planning and delivery decisions through an analysis of the structures, processes, and relationships that support and impede family involvement in system level service planning and delivery decisions in established service systems for children and adolescents with Serious Emotional Disturbance (i.e., systems of care). This study sought to identify the core components and strategies employed by systems of care to successfully engage families as full partners in system level decision making, and to develop a framework that depicts how these processes are carried out.

To gain a clearer understanding of the role of families in service planning and delivery decisions at the system level, the following research questions were addressed:

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 Approach

To answer the research questions presented above, extant literature was examined to develop a framework for implementing family driven care within a system of care. This included a review of frameworks within child and adult mental health but also many frameworks external to the mental health field. Frameworks were examined within primary care medicine, education, and public and non-profit organizations and systems as well as for-profit organizations. These frameworks included patient and consumer empowerment, parent and family empowerment, stakeholder empowerment, employee empowerment, and an examination of shared and collective leadership. These were examined for potential contributions to understanding how families might be better integrated into system level service planning and delivery decisions.

After the framework was developed, a secondary analysis of qualitative data (QSA) was conducted. These data were collected through a five-year federal research project entitled Case Studies of System Implementation (CSSI; Research and Training Center for Children’s Mental Health, 2004). This qualitative research study used a multi-site embedded case study design to examine the development of systems of care. A total of six systems of care were studied during this research project. Purposive sampling was used to identify systems of care for inclusion in the study.

The secondary data analysis used the following data from the original study: document review, semi-structured interviews with key system stakeholders, observations
of meetings, and a ratings exercise completed by interview participants. A team-based approach to the secondary analysis of these data was used, and the initial framework was revised to include findings from the secondary analysis.

Focus groups were then conducted with individuals from system of care communities currently funded through the CMHI, in order to receive feedback on the revised framework based on their system of care experiences. Purposive sampling was used to identify participants for the focus groups. Separate focus groups were held with 1) Lead Family Contacts, and 2) Principal Investigators and Project Directors. Data from the focus groups were used to further refine the framework.

**Rationale and Significance**

The topic for this research study was identified from an exploration of system of care development conducted within six system of care communities throughout the United States. Although the original study focused on how established system of care communities developed their systems, a theme around family driven care emerged from the data. One particularly notable observation was that even well-established systems of care appeared inconsistent in engaging families in service planning and delivery decisions, and although system leaders worked diligently to engage families in service planning and delivery decisions at all levels of the system, they were often challenged by how to effectively carry out this activity and expressed a need for further guidance on how to do so. Findings from this study will help communities understand the implementation of family driven care and the strategies employed by communities that have successfully engaged families in system level service planning and delivery decisions.
Assumptions

There are five underlying assumptions that guide this research project:

1. Families want to be involved in service planning and delivery decisions at the system level.
2. Providers value families as full partners in service planning and delivery decisions at the system level.
3. Families and providers can work collaboratively towards system transformation.
4. Having families as full partners in service planning and delivery decisions at the system level is beneficial to youth and family services within the system.
5. Families would be more involved in service planning and delivery decisions if system of care partners had more insight into how to engage them in the process.

Key Terminology

There are several terms used regularly in the field of children’s mental health that may need clarification for use within this dissertation. First, the phrase “children’s mental health” is often used to describe mental health services for all children and adolescents until they are eligible for services within the adult mental health system. Other commonly used terms are defined below.

**Serious Emotional Disturbance (SED):** A population that includes children or adolescents: 1) under 18 years of age; 2) who have emotional problems that are disabling based on social functioning criteria
(impairments that affect functioning in home, school, and community settings); 3) have multiple agency needs; 4) have a diagnosable mental health disorder; and 5) have a persistent (at least 1 year in duration) mental or emotional disorder (Stroul, 1983; Stroul & Friedman, 1986).

System of Care (original definition): “A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents” (Stroul & Friedman, 1986, p. 3). Note: This definition was revised in 1994 to “children and adolescents with severe emotional disturbance and their families” (Stroul & Friedman, 1994, p. 3).

System of Care (a recently revised definition and used within this dissertation): “An adaptive network of structures, processes, and relationships grounded in system of care values and principles that provides children and youth with serious emotional disturbance and their families with access to and availability of necessary services and supports across administrative and funding jurisdictions” (Hodges, Ferreira, Israel, & Mazza, 2010, p. 6).

System of Care Community: A commonly used referent when describing systems of care within the Request for Applicants for CMHI, a system of care community refers to the entire system of care (within a bounded area) that serves children and adolescents with SED and their families in a community-based setting. This may include a state, region within a state,
county, territory, Native American and tribal organization, or the District of Columbia.

**Family:** For the purpose of this dissertation, family generally refers to biological parents but also extends to step-parents, adoptive parents, foster parents, surrogate parents, extended family members, or other caregivers who are involved in primary decision making for a child or adolescent.

**Family Driven Care:** 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 (National Federation of Families for Children’s Mental Health; FFCMH, 2010).

**System Level:** Refers to linkages between child-serving agencies such as mental health, child welfare, juvenile justice, and education in a community-based setting with a continuum of services and supports. This level is often associated with the overall structure, organization, and financing within the system (Rosenblatt, 1998).

**Program Level:** Level that includes programmatic components such as the type of placement or program—inpatient or outpatient services, therapeutic foster care, or case management (Rosenblatt, 1998).

**Clinical/Individual Treatment/Practice Level:** The way in which direct care staff interact with the youth, family, and their support systems (Rosenblatt, 1998).
**Structures:** Specified roles, responsibilities, and authorities that denote organizational boundaries and enable an organization to perform its functions (Hodges, Ferreira, Israel, et al., 2010).

**Processes:** Methods and procedures for carrying out organizational activities and often involving sequences or sets of interrelated activities that enable an organization to perform its functions (Hodges, Ferreira, Israel, et al., 2010).

**Relationships:** Trust-based links creating connectedness across people and organizations (Hodges, Ferreira, Israel, et al., 2010).

**Value:** An ideal accepted by an individual or group (Value, n.d.)
Chapter Two:

Literature Review

One of the challenges of the system of care philosophy is a lack of theoretical orientation. Although the originators of systems of care spoke of systems metaphorically, Hodges, Ferreira, and Israel (in press) argue that a grounding in systems theory is lacking from their definition and description of the concept. This literature review will begin with a description of the system of care philosophy—its definition; original purpose; impact not only on outcomes for children and families but also its influence on legislation, court rulings, and other state and federal initiatives; and its historical evolution. The review will also include a description of systems theory and systems thinking and practice within the context of change within systems of care.

The discussion of systems of care and systems theory, thinking, and practice will provide a foundation for further discussion of family driven care within children’s mental health as well as empirically-based frameworks on stakeholder involvement that have applicability to family driven care within systems of care. The discussion of family driven care will include literature related to the evolution of the role of family members in individual treatment and system level decision making, related initiatives and legislation, and why family driven care is critical to systems of care. It will also include challenges with and strategies for implementing family driven care. The literature review will conclude with an examination of a number of frameworks being used to engage
family members, consumers, and other stakeholders in various levels of decision-making. Relevant frameworks examined include models within child and adult mental health, primary care medicine, and education as well as consumer involvement in non-profit organizations or systems. Finally, frameworks related to shared decision making and shared leadership within the organizational literature will also be reviewed to determine the potential contributions to understanding how families might be better integrated into system level service planning and delivery decisions. A summary of this literature follows.

**Systems of Care**

**History.** The system of care concept was introduced in 1986 with the publication of Stroul and Friedman’s *A System of Care for Severely Emotionally Disturbed Children and Youth* (revised in 1994 to *A System of Care for Children and Youth with Severe Emotional Disturbances* to reflect person-first language), at a time in which the lack of services and supports for children and adolescents with serious emotional challenges was drawing a great deal of attention. Prior to the publication of this monograph, several things occurred that highlighted the issue of inadequate services for children and adolescents with serious emotional disturbance (SED). Dating back to 1969, the Joint Commission on Mental Health of Children published a report entitled *Crisis in Child Mental Health*, which emphasized the unmet needs of children and adolescents who were challenged with mental health issues. Almost a decade later, the President’s Commission on Mental Health (1978) supported the conclusions of the Joint Commission. However, Jane Knitzer’s influential monograph *Unclaimed Children*, published in 1982, is generally viewed as the impetus for a shift in how these youth are served throughout the
country. *Unclaimed Children* not only highlighted the inadequate and fragmented services for children and adolescents with SED throughout the United States but also challenged the federal government to improve services and supports for these youth. The government’s response included the initiation the Children and Adolescent Service System Program (CASSP) through the National Institute of Mental Health, which provided funding for states to create service systems for children and adolescents with SED. The initiative included two components in particular that have strongly impacted systems of care: 1) a definition of the SED population (i.e., characteristics of children and adolescents who meet criteria for SED classification); and a list of CASSP principles for serving these youth (Day & Roberts, 1991). These components were not only incorporated into seminal works such as Stroul and Friedman’s system of care monograph, but are regularly referenced within system of care literature and practice today (for example, Chorpita & Donkervoet, 2005; Hodges, Ferreira, Israel, & Mazza, 2010; Stroul & Blau, 2008).

In their 1986 monograph, Stroul and Friedman (1986) defined a system of care as “a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents” (p. 3). Over time, as researchers and practitioners have learned more about the development and implementation of systems of care, changes to the system of care definition have occurred (see Stroul and Friedman, 1994 for revision to person-first language; see also CMHS 2006; Hodges et al., 2010; Pires, 2002; Stroul 2002 for additional definitional changes).
The purpose of the original system of care monograph was to provide a guide for communities to develop integrated services for children and adolescents with SED and their families. The original monograph highlighted two core values—that services should be 1) child-centered (with the needs of the child and family dictating the types of services provided), and 2) community-based (Stroul & Friedman, 1986). These system of care values have since been expanded, emphasizing family driven and youth guided care as well as cultural and linguistic competence (CMHS, 2006; Stroul, Blau, & Sondheimer, 2008; Stroul & Friedman, 1994). The authors also included CASSP’s definition of SED within the system of care context, which includes children or adolescents less than 18 years of age (now expanded through age 21) with emotional problems that are disabling based on social functioning criteria (impairments that affect functioning in home, school, and community settings). These youth have multiple agency needs, a diagnosable mental health disorder, and a persistent (at least 1 year in duration) mental or emotional disorder (Day & Roberts, 1991; Stroul, 1983; Stroul & Friedman, 1986, 1994; USDHHS, 2010).

Although many systems of care have expanded their populations to include early intervention and prevention services, systems of care are generally viewed as serving the more narrowly defined population of youth.

Since its inception, the term system of care has become widely used and has moved beyond the purview of mental health. This language has become commonly used terminology within many other child serving disciplines, such as child welfare, juvenile justice, and education (Hodges et al., 2010). The system of care concept was originally intended to include a network of services and supports across the domains of mental health, social services (i.e., child welfare), education, physical health, substance abuse
services, vocational services, recreational services, and juvenile justice. In reality, partnering agencies within child/adolescent systems of care most often include mental health services, child welfare, education, and juvenile justice. Confusion sometimes occurs in that individual child serving sectors may refer to themselves as a system of care. For example, it is not uncommon to hear the term “system of care” used in educational legislation or in practice. In fact, this terminology is even found within the No Child Left Behind Act of 2001. The same referent may be used within child welfare or juvenile justice. More accurately, these service sectors, even if not working within a “system of care” have incorporated system of care values and principles within their practice. Because a defining characteristic of a system of care is the linkage of all system partners across administrative and funding structures with the goal of serving the youth and family, the more comprehensive use of the term will be reflected throughout this dissertation.

**Related legislation and litigation.** The intent of systems of care includes that networks between the above mentioned partners are developed through voluntary collaborations across agencies rather than mandated efforts (Hodges, Hernandez, & Nesman, 2003); however, political influence, legislation (both federal and state), and class action litigation have also effected powerful change within systems of care. A few are highlighted below.

As Hodges and colleagues (2010) note, the impact of the system of care concept is evidenced by its reference within the Surgeon General’s report on children’s mental health (U.S. Department of Health and Human Services, 1999), the report of the Surgeon General’s Conference on Children’s Mental Health (U.S. Public Health Service, 2000),
and the report of the President’s New Freedom Commission on Mental Health (2003). In particular, the Surgeon General’s 1999 report highlighted positive outcomes related to systems of care (as well as addressing some of the more controversial research and outcomes related to systems of care).

Litigation related to the provision of comprehensive, community-based mental health services for youth with SED has met with a great deal of success over the last 30 years. Willie M. v. Hunt (1979) is recognized as one of the first successful lawsuits related to the denial of educational services and appropriate mental health treatment for youth within institutional settings. This resulted in the development of a full continuum of services within North Carolina. Other notable class action lawsuits that have forced the expansion of mental health services to include comprehensive, community-based service provision include Los Angeles’ Emily Q. v. Bonta (1998), Hawaii’s Felix v. Cayetano Consent Decree (1993), Katie A. v. Bonta (2002), and Rosie D. v. Romney (2006). Recently filed lawsuits in Washington State (T.R. et al. v. Susan N. Dreyfus, 2009) and Mississippi (J.B. et al. v. Barbour et al., 2010) emphasize the continued struggles of youth and families to access necessary services and supports.

As communities work to transform their mental health service systems, whether it be in response to litigation or a voluntary decision by system partners to provide more comprehensive, effective, community-based services, the passing of certain pieces of legislation have provided much needed funding and regulation for these efforts. For example, the federal Community Mental Health Service Block Grant program (originally established in 1981 and has had several iterations since that time) and the Substance Abuse and Mental Health Services Administration’s (SAMHSA’s) 1992 Comprehensive
Community Mental Health Services for Children and Their Families Program (also known as the Children’s Mental Health Initiative; CMHI) have provided nearly $1.5 billion dollars to states, regions, counties, territories, Native American and tribal organizations, and the District of Columbia aiming to create more comprehensive, community-based mental health services (IFC Macro, 2010). State legislation such as the California AB377 Evaluation Project (1988), Vermont Act 264 (1988), and the Comprehensive Services Act (1992) also illustrate funding and regulatory support for these systems change efforts.

**Bounding a system of care.** In discussing systems change efforts, Foster-Fishman and Droege (2010) emphasize that a critical step towards successful transformation is to establish a system’s boundaries. They note that gaining clarification of boundaries includes articulation of the target problem and identification of available resources within the system. They also note, however, that boundaries must be flexible to meet the needs of a changing environment.

For the purpose of this research project, each system of care includes all partner agencies/providers involved in the care of the youth. This may consist of traditional providers such as mental health, child welfare, juvenile justice, education, and family organizations as well as some less prominent partners such as primary health care, local university partners (often assisting in evaluation efforts and technical assistance), early intervention providers, and faith-based organizations. The system of care philosophy, its values, and principles have significantly shaped local, state, and federal policy for over 20 years (Burns & Hoagwood, 2002; Kutash et al., 2005; Stroul & Blau, 2008), and will continue for many years to come.
A Systems Perspective

As noted in the introduction to this chapter, although the originators of systems of care referred to systems in a metaphorical sense, the theoretical underpinnings of the system of care concept were not clearly articulated within the original monograph (Hodges, Ferreira, & Israel, in press). The discussion below aims to provide a theoretical context by which to consider the system of care framework. It will begin with a discussion of systems theory to establish a context of systems thinking and practice and will examine the alignment of these overarching concepts with systems of care.

General Systems Theory. The area of study referred to as General Systems Theory is often attributed to the work of the biologist and philosopher Ludwig von Bertalanffy. Although terms such as “systems” and “systems thinking” were used prior to the publication of some of his more commonly referenced works, it was primarily von Bertalanffy’s work—particularly in the 1950s and 1960s—that developed this concept into a scientific movement (Capra, 1996). In von Bertalanffy’s seminal work, General Systems Theory: Foundations, Development and Applications, he defines general systems theory as a “general science of ‘wholeness’” (von Bertalanffy, 1968, p. 37) and notes that individual elements of an organism or social phenomenon, when taken together, create a complex, emergent whole. This perspective was contrary to the position of most scientists of the time as they “tried to explain observable phenomena by reducing them to an interplay of elementary units investigatable independently of each other” (von Bertalanffy, 1968, p. 36-37). In fact, von Bertalanffy stated that a system is not completely understood when each of its parts are examined in isolation. Physicist David Bohm (referenced by Senge, 1990) in discussing deconstructing an entity, examining it,
and attempting to put it back together, used the analogy of reassembling fragments of a broken mirror expecting to see a true reflection. He adds that one will eventually stop attempting to see the whole.

von Bertalanffy strongly encouraged a broader application of General Systems Theory (GST) to fields of study beyond biology and stressed that concepts such as “organization” and “wholeness” are present not only in biology but in behavioral and social sciences and are necessary in understanding living organisms and social groups. Systems theory has greatly evolved since von Bertalanffy’s original work to include many other disciplines. Although von Bertalanffy’s work focused on bounded systems such as biological systems (even his examination of GST in psychology and psychiatry is patient-specific), these concepts lay the foundation for work of scholars in other disciplines. Fritjof Capra’s focus on all levels of a living system, including individual organisms, social systems, and ecosystems (e.g., Capra, 1996) as well as Peter Senge’s work related to organization and management systems (e.g., Senge, 1990) highlight the broader application of GST. Senge emphasizes that considering organizations within a systems theory framework is important but adds that successful organizations are “learning organizations,” in which employees within the organization choose to constantly learn and grow—allowing them to make team-based decisions that help to move the organization forward. In fact, developing a learning organization has been identified as a critical activity for the success of non-profit organizations (Green, 2004). This idea of applying GST to organizational decision making lays the foundation for systems thinking and practice, which will be discussed in the next section.
**Systems thinking and practice.** The summary above describes systems *theory*, a framework that one could easily argue has significant relevance to systems of care. However, because systems of care are a) complex service and support systems, b) located in a “real world” setting, and c) expected to respond to the ever-changing needs of the population as well as political and funding pressures, it is important to consider systems not only in a theoretical sense but also in practice. Checkland defines systems thinking as “thinking about the world outside ourselves, and doing so by means of the concept ‘system’” (Checkland, 1999, p. 3). He emphasizes the use of systems ideas in trying to understand the world’s complexity, in which systems *thinking* helps us organize our thoughts, and systems *practice* suggests using the results of this thinking to guide our actions. Checkland’s work related to human organization systems (e.g., Checkland, 1999) reflects the *application* of systems theory to real world settings. Checkland notes that complexity, social phenomena, and “real world problems” are difficult to study with traditional scientific methods, and introduces the concept of Soft Systems Methodology (SSM) as an approach to examine these phenomena. Checkland uses the term “soft” because he emphasizes that these systems are not clearly defined and notes that the *process of inquiry* is systemic. The principles of SSM reflect the complexity of these systems and the activity that occurs within: 1) there is inquiry that occurs in the real world and includes a complexity of relationships; 2) there are systems of purposeful activity that are based on articulated world views; 3) there is action to improve the system (based on accommodations that are made to satisfy conflicting interests); and 4) the inquiry, in principle, is never ending (Checkland, 1999).
Foster-Fishman, Nowell, and Yang (2007) hypothesize that in general, systems change efforts in the fields of human services and community-based change ignore the systemic and complex nature of the targets of their change efforts. In addition, Foster-Fishman and Droege (2010) emphasize that if entire systems are the targets of intended change, it is critical to have frameworks that address the characteristics and dynamic nature of a complete system.

**Systems theory’s alignment with systems of care.** The previous sections provided a review of General Systems Theory and systems of care. What relevance do systems theory, thinking, and practice have to the implementation of systems of care? Von Bertalanffy’s notion of “wholeness” in which individual elements, when taken together, *create a complex, emergent whole* clearly supports the concept of a system of care. This idea, in consort with the notion that the characteristics of individual elements should not be viewed in isolation but instead should be examined as an integrated whole (because of the idea that these individual elements when taken together will *create an entity that takes on different characteristics* than the individual parts), lay the foundation for considering the powerful effect that an integrated network of services and supports may have within a community. A core characteristic of a system of care is a linkage across people, organizations, and service sectors (Hodges, Friedman, & Hernandez, 2008) to meet the needs of youth with SED and their families. Stroul and Friedman (1986) explain that the system of care framework should be thought of as function-specific—not agency specific—as the entire network comes together as a whole to support the youth and family reducing siloing of services. Moreover, in viewing systems as continuously constructed and reconstructed by individuals and groups in an ongoing
process that reflects the complexity of real world experience (Capra, 1996; Checkland, 1999; Senge, 1990), systems theory can be used to understand systems of care as dynamic entities that are sensitive to local conditions, and system development as requiring understanding of how influence in one area of a system might accomplish broader system change. In fact, it is difficult not to see how Checkland’s application of GST—as he describes complex phenomenon in real world settings, purposeful activity with an aim towards improvement, and never-ending inquiry—aligns with the system of care concept and its impact on mental health transformation across the country.

Finally, the system of care definition can be examined within the same context. The original definition described a system of care as “a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents” (Stroul & Friedman, 1986, p. 3). In a recently suggested modification to the definition, Hodges and colleagues offered an addition to the definition that reflects the complex and adaptive nature of a system of care. This definition states:

A system of care is an adaptive network of structures processes and relationships grounded in system of care values and principles that provides children and youth with serious emotional disturbance and their families with access to and availability of necessary services and supports across administrative and funding jurisdictions (Hodges et al., 2010, p. 6).

In addition to the idea that services and supports are available across administrative and funding jurisdictions (by their very nature suggesting a system of integrated elements, as mentioned above), the definition includes two components that
specifically support the inclusion of systems theory, thinking, and practice into the system of care concept. These include:

- **Network:** Used in the original definition, the concept of a network has been present in each iteration of the system of care definition (see CMHS, 2006; Hodges et al., 2010; Pires, 2002; Stroul, 2002; and Stroul & Friedman, 1986, 1994 for details). Capra (2002) and Schensul and colleagues (1999) refer to this as a quality of linkages across people organizations, and communities. This interconnectedness allows for an individualized and non-linear response to the needs of youth and families, and contrasts with the fragmentation of services and supports that occurs when a system of care is not present (Hodges et al., 2008; Hodges et al., 2010).

- **Adaptive:** This concept was added to the definition because it describes the system’s ability to respond to a changing environment and context (Hodges et al., 2010). This incorporates the concepts of action, reaction and learning over time (Holland, 1995) and is reflective of Senge’s description of a learning organization (1990) and an ongoing process (among multiple interconnected elements) based on experience (Checkland, 1999).

Not only have these concepts been viewed as important to the system of care definition, but the characteristics of adaptation and networks within systems of care are critical as systems transform from provider driven to family driven.
Family Driven Care

The previous sections of this chapter provided an overview of how the system of care concept emerged and has impacted services for children and adolescents with SED and their families. In addition, a description of systems theory, thinking, and practice and their suggested links to the system of care concept have been included. These descriptions are critical in order to provide a context in which to view the role of families in mental health service planning and delivery decisions. But what is the role of the family in this process? What requirements do systems of care have in involving families in planning and decision-making? Why is family involvement necessary? Finally, how are they ensured a voice in the service delivery process and what are some of the challenges in having parents as full partners within the system of care? This section of the review aims to answer these questions. The literature review on family driven care is specific to: 1) family involvement at the organizational or system levels (with less focus on family driven care at the individual treatment level, which has large literature base of support), and 2) children and adolescent (versus adult) mental health.

While the CASSP principles and system of care framework began to impact the provision of services and supports for children and adolescents with SED, researchers and policy makers, with the assistance of family advocacy organizations, began to take note that family unit as a whole was being ignored as an important contribution to the treatment process. This began in the mid 1980s with funding and research activities through the Research and Training Center on Family Support and Children’s Mental Health at Portland State University and culminated in the emphasis on Family Driven
Care within the President’s New Freedom Commission on Mental Health (2003). These activities will be described in detail further in this literature review.

In 1990, Friesen and Koroloff, some of the first researchers to explore and address the issue of family engagement in systems of care (and have continued their influential work over the last 20 years), found that 1) systems of care were focusing on services and supports for the child/adolescent in isolation of the family unit, 2) the focus for these youth was only on the provision of mental health services (i.e., excluding services and supports available through other service domains), 3) the focus was on formal services while ignoring informal supports that might be available to the youth and family, and 4) resources and expertise of families were not being utilized. Although all of these findings are critical to serving children and adolescents with SED and continue to challenge the field, the fourth finding is foundational to the concept of family driven care, which will be described below.

**Family driven care defined.** The use of the terminology *Family Driven Care* within children’s mental health is often attributed to the 2003 President’s New Freedom Commission on Mental Health. Goal 2: Mental Health Care is Consumer and Family Driven (p. 8), envisions that “consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved” (p. 8). Although the Commission identified this critical goal, it did not further define the term Family Driven Care, instead offering broad recommendations such as, “Consumers’ needs must drive the care and services that are provided” (p.27). These broad statements, possibly intended to avoid being overly prescriptive, leave room for a considerable amount of interpretation. This provided an opportunity, however, for the FFCMH and the
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. (FFCMH, 2010; Osher, Osher, & Blau, 2006; USDHHS, 2005).

Also included with this definition was a list of guiding principles for family driven care:

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 and choices about the right services and supports for individual children and their families.

3. All children, youth, and families have a biological, adoptive, foster, or surrogate 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.

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. (FFCMH, 2010).

The above principles reflect the importance of cultural and linguistic competence, addressing mental health disparities, the family’s active role in evaluation, and the
advocacy role of families and family-run organizations—modifications to the original principles developed through the FFCMH and CMHS (Osher, Penn, & Spencer, 2008; Osher, Osher, & Blau, 2006). These modifications to a fairly new concept reflect a field struggling to clearly articulate the role of families.

Levels of family driven care. It is important to consider the various levels within a system, as they lay the foundation for understanding the various points at which families can be engaged within the system as well as clarity around assessing outcomes within a system of care. Rosenblatt (1998), in discussing system of care outcomes, provides a clear differentiation between three levels: 1) Clinical (often referred to as Individual Treatment or Practice) Level; 2) Program Level, and 3) System Level.

Clinical/Individual Treatment/Practice Level. This level refers to the way in which direct care staff interact with the youth, family, and their support systems (Rosenblatt, 1998). This may include various psychotherapy approaches, case management, behavioral interventions and continuum of supports. These interventions are not exclusive to mental health staff but include direct care services and supports from all system partners, including, for example, child welfare, education, or juvenile justice.

Program Level. This level includes more broad programmatic components such as the type of placement or program—inpatient or outpatient services, therapeutic foster care, or case management (Rosenblatt, 1998).

System Level. This level refers to linkages between child-serving agencies such as mental health, child welfare, juvenile justice, and education in a community-based setting with a continuum of services and supports. This level is often associated
with the overall structure, organization, and financing within the system (Rosenblatt, 1998).

It is important to note that depending upon the organizational structure of each system of care, the program level may have very different characteristics. For example, a specific partner agency may be viewed as a “program,” and families may have a very active role in service planning and delivery decisions within a specific partner agency (e.g., child welfare). Alternatively, a “program” may be a specific cross-agency program but is administered at a meso-level, such as a wraparound program that includes multiple system partners for service planning and implementation. Thus, involvement of families at the program level can be multilayered, not clearly defined, and is often not consistent across systems of care. In addition, the CMHI (the federal funding program for systems of care) recognizes two levels within its cooperative agreement request for applications: Required Mental Health Support Services (i.e., individual treatment level), and the Infrastructure Development Level (i.e., system level). Therefore, within this dissertation discussion of family involvement is focused on these two distinct levels.

**History and evolution of families in mental health services.** The role of families within mental health service systems has seen much change over the last century. Friesen and Stephens (1998) describe this evolution by organizing the expanding role of these families into six distinct roles. This description, supported by additional literature (Duchnowski & Kutash, 2007; Lourie & Katz-Leavy, 1991), begins with the concept of families as causal agents for a child’s mental health challenges.

- *Family members as context.* Acknowledging that family members are part of the environment of the child, in the early to mid-1900s, family members
were viewed as responsible for the behavioral and emotional challenges of the child and were not involved in a child’s treatment (Duchnowski & Kutash, 2007). Friesen and Koroloff (1990) note that ignoring the role of families in the treatment process was not accidental “but is related at least in part to deep-seated beliefs about the nature and cause of emotional disorders in children” (p. 14). It should be noted that although advances in research have been able to identify etiology and effective treatment for mental disorders, the “blamed and shamed” (Spencer, 2008, Forward) stigma persists.

- **Family members as targets for change and recipients of services.** Friesen and Stephens (1998) describe families as passive recipients of interventions. This idea is supported by Duchnowski and Kutash (2007) who note that families started to become more actively involved in the treatment process in the 1950s and 1960s.

- **Family members as partners in the treatment process.** Friesen and Stephens (1998) describe this as “Families as Allies” (Bryant-Comstock, Huff, & VanDenBerg, 1996; McManus & Friesen, 1986) in the individual treatment process, in which there is a sharing of power and responsibility for improved outcomes for the child and family. Duchnowski and Kutash (2007) note that in the 1960s and 1970s, families of children with developmental disabilities began advocating for increased family participation in children’s health services. Unfortunately, the mental health field saw a delay in this advocacy, and the mid to late 1980s reflected a
shift in which mental health professionals began to question strongly-held beliefs that family members were responsible for their child’s mental health challenges (Duchnowski & Kutash, 2007; Lourie & Katz-Leavy, 1991). Additionally, in the 1990s services began to focus on child and family strengths, and collaboration became a goal for all participants (Duchnowski & Kutash, 2007).

- **Families as service providers.** Family members expanded their roles in peer support and mentorship for other families. This role is often reflected in case management work, peer-to-peer support and advocacy, training, and mediation (Friesen & Stephens, 1998; Hoagwood, 2008; Kutash, Duchnowski, Green, & Ferron, 2010).

- **Family members as policy makers and advocates.** Although Friesen and Stephens (1998) described the six roles of family members prior to 2000, their anticipation of how families’ roles would expand were on point. Family members as policy makers and advocates reflect broad advocacy activities for family members and family organizations. These family organizations, which may have a state-wide or local constituency and are often linked nationally to other chapters provide emotional support, share information, and advocate for improvements in policies and services (Koroloff, Friesen, Reilly, & Rinkin, 1996). The idea of family members as active members in policy decisions at the state and federal levels has been particularly reflected in activities over the last decade. The 2000s have shown a strong surge in the active role of families within mental
health service systems and began the introduction of family driven care within systems of care (Duchnowski & Kutash, 2007). This includes the final role that Friesen and Stephens (1998) describe—Family members as evaluators and researchers.

- *Family members as evaluators and researchers.* Family members have taken an active role as evaluators, consultants, and advisors, as anticipated by Friesen and Stephens. In fact, the role of families as evaluators is now a requirement for system of care communities who receive CMHI funding. In addition, with a push towards participatory action research, families are viewed as valuable members of research teams. These last two roles—those of policy makers and advocates as well as evaluators and researchers—have occurred fairly simultaneously within systems of care.

**Political and legislative impacts.** As mentioned in the section that defined Family Driven Care, political influences such as the Surgeon General’s Report (1999) and the President’s New Freedom Commission (2003) have significantly impacted how families should be received within the mental health service system. However, these political influences were not the first time there was a focus on transforming mental health care to more fully include families within the treatment process. Beginning in 1984, the National Institute of Mental Health (NIMH) and National Institute on Disability and Rehabilitation Research (NIDRR) funded the Research and Training Center (RTC) on Family Support and Children’s Mental Health at Portland State University (Bryant-Comstock et al., 1996). The Center’s focus on family driven care provided the opportunity for researchers to examine and work to expand the role of families as
partners within the field of mental health. Although the Center’s focus has recently shifted, research and advocacy for families continues to be a priority throughout the country. The RTC’s 1986 conference, entitled Families as Allies was one of the first conferences on the role of families in improving services, supports, and family advocacy (Bryant-Comstock et al., 1996). Shortly thereafter, the RTC hosted the Next Steps meeting, in which plans were developed to address core family and child issues. This meeting was cutting edge, in that it had full involvement of families in development and facilitation of the meeting. (Bryant-Comstock et al., 1996).

In 1988, CASSP funding began to provide grants to develop statewide family networks. This funding has expanded over the years, and CMHS now funds over 42 family networks and a technical assistance center (Osher, Penn, & Spencer, 2008). In 1989, the FFCMH was created from a steering committee that was identified during the Next Steps meeting. The FFCMH, a family-run organization for families with youth with emotional, behavioral, and mental health challenges, provides advocacy at the national level, offers leadership and technical assistance to family run organizations, and collaborates with family-run and other child serving organizations to improve mental health care throughout the country. Since its inception, the FFCMH has played an active role in the development and implementation of systems of care and—along with the National Alliance for the Mentally Ill (NAMI)—has become a powerful voice in mental health advocacy. As noted by Friesen and Stephens (1998), these organizations have taken a leadership role in mental health advocacy, system planning, quality improvement, program evaluation, parent education, and development of parent mentoring programs (Friesen & Stephens, 1998), which has positively influenced providers’ perceptions of
families as partners in treatment, service planning, and delivery. This can be described as a culture change within mental health service delivery (Duchnowski & Kutash, 2007).

CMHS/SAMHSA has funded communities to develop and implement systems of care. Since the initiation of the cooperative agreement in 1992, the Request for Applications (RFA) for the CMHI has, not surprisingly, had several modifications. A very noteworthy modification, however, includes the role of families within the funded communities. Prior to 1997, the RFA spoke of family-focused care, ensuring that the service and support needs of the child and family were being met. In 1997, the RFA discussed families as partners in the planning process. In 1999, sites were required to have or develop a family support organization, and in 2002, a full-time Key Family Contact to attend the grantee meetings became a requirement of the funded communities. This was the point in which families began to be meaningfully incorporated into evaluation activities and planning at both the individual and system levels. In 2005, the RFA began to use the terminology family driven care language and provided a definition within the RFA. In addition to evaluation activities, the RFA emphasized families’ sharing in decision-making and responsibility for outcomes. Finally, the RFA specified that the full-time family position (re-titled Lead Family Contact) take a very active role in planning, implementation, and evaluation throughout the system (Sondheimer, 2006).

The Lead Family Contact serves as an advocate for other family members in the system, represents families on the governance body, and conducts outreach. The funded community is also required to plan sustainability of this position beyond funding period (USDHHS, 2005). These modifications to the RFA, which have a significant impact on family involvement because of requirements tied to funding, stand today.
**Perceptions of families**

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blamed for their child's mental health challenges</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipients of services</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partners in treatment process</td>
</tr>
</tbody>
</table>

**CMH RFA Requirements**

<table>
<thead>
<tr>
<th>Terminology Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-focused</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CMH RFA Launched</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families are partners in planning, implementation, management, and development of services at individual level</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent at grantees meetings</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Onsite family support organization or network required for funding</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>More active participants in individual treatment</td>
</tr>
</tbody>
</table>

**Family Support and Advocacy**

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocates for their child’s treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rate satisfaction of services</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased participation in treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impact policy through advocacy</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Incorporated into evaluation activities</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Rate program effectiveness</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partners in decision making at individual treatment and system levels</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Active participants in evaluation</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Advocates/ supporters for their child and others</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Family involvement (1990)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Family professional partnerships (2000)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Onsite family support organization or network required for funding</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Must have full family participation in system and service development</td>
</tr>
</tbody>
</table>

**Family Support and Advocacy**

<table>
<thead>
<tr>
<th>Families:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families of children with disabilities began to advocate for services</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NAMI created</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Increased advocacy for participation in individual treatment</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>RTC Portland’s Families as Allies and Next Steps conference</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Funding of statewide family networks</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>FFCHM created</th>
</tr>
</thead>
</table>

**Figure 1. Milestones within the Family Movement**

37
The timeline in Figure 1 highlights some milestones within the family movement over the last century. This figure illustrates the heightened activity that has occurred during the last 15-20 years. It should be noted that this timeline reflects a broad overview of progress towards engaging families in mental health service systems, and individual systems vary significantly on how families are involved.

Legal and political issues related to family driven care cannot be considered in isolation of legislation, political influence, and court rulings for systems of care in general. The prior discussion of system of care legislation and litigation reflected a focus on inadequate or inappropriate services and supports for youth with emotional or behavioral challenges. There are a variety of reasons that youth may not receive services and supports at a level of treatment consistent with their needs. However, placement in highly restrictive settings without access to a continuum of appropriate services and supports is in direct conflict with the guiding principles of family driven care—in particular that families are empowered and share in decision-making, that families and youth are given accurate and complete information to assist in decision making, and that families have a voice in advocating for their youth. One of the most egregious and well-documented violations of these principles relates to parents forced to relinquish custody of their child or adolescent to the state in order for the youth to receive needed services. As state wards, these youth are then able to access Medicaid-covered services. This, according to Friesen and colleagues (2003), is the primary reason parents must relinquish custody of their children with serious emotional disturbance. Some states have passed legislation that prohibits custody relinquishment only for the purpose of allowing a child...
to access out-of-home services, however, this problem persists (Friesen, Giliberti, Katz-Leavy, Osher, & Pullmann, 2003).

In a 25 year retrospective of systems of care, Friesen (2010) spoke of lessons learned related to the family movement. Although she offered many highlights, one point is particularly salient to this discussion. She notes that changes in how families and youth are recognized within systems of care are linked to government-stimulated initiatives--mandates, incentives, and consequences (Friesen, 2010). In all likelihood, these powerful initiatives will continue to be necessary to fully transform the children’s mental health field into one in which families are truly empowered.

The logic of implementing family driven care. Knitzer and Cooper (2006), in describing areas for policy action, note that it is important to focus on embedding family perspectives into infrastructure. They further state that although progress has been made, there are great disparities across states related to funding for family advocacy. In addition, within organizations there is much variation; for example, some organizations having paid positions for family members. Finally, Knitzer and Cooper note that even when family involvement is valued, family empowerment in making decisions at the system level can create considerable conflict within the system. These authors articulate some of the challenges in family engagement at the organizational and system levels, and for some, it may raise the question: “If this is such a challenge to carry out, why is it so important to continue work toward family driven care?”

The previous sections described many of the efforts that have gone into transforming our children’s mental health system into one that has families as major decision makers at the individual treatment and system levels. Thus far, the discussion
has focused on history and evolution of family driven care as well as legislation related to this movement. Beyond a mandate for family driven care within federally funded system of care communities, however, what evidence supports the role that is now viewed as critical within children’s mental health? As Friesen and colleagues note, one can examine the theories of Freud, Piaget, and Erikson to appreciate the important role that parents play in the development of their children (Friesen, Pullmann, Koroloff, & Rea, 2005). The purpose of this section is not to highlight the impact of parents on child development but to focus on current research evidence related to family, or parental, involvement in decision making at the individual treatment and system levels and their effect on improved outcomes for children and families. This discussion will also touch upon a less researched but no less important values argument: *Families have the right to be involved in decisions that affect their children.*

**Outcomes argument.** One of the more comprehensive examinations of outcomes related to family involvement within the field of mental health was conducted by Hoagwood in 2005. Similar to some of Friesen and Stephen’s 1998 findings, Hoagwood found that the role of families consisted of being recipients of interventions, co-therapists (i.e., service providers), and various roles related to “the process of involvement” (i.e., more active engagement, empowerment, or as part of a therapeutic alliance). Hoagwood’s synthesis of family-based services in children’s mental health, focused on all three categories, but process of involvement is most germane to this discussion. Disappointingly, Hoagwood’s comprehensive review illustrated the dearth of empirically-based literature related to family involvement at the system level, with most data reflecting outcomes at the individual treatment level. However, Hoagwood’s
synthesis of the process of involvement of families highlighted improved treatment retention, satisfaction, and levels of active participation in service planning (Hoagwood, 2005). There were a couple of particularly noteworthy studies within Hoagwood’s synthesis. A training program and assessment of parent empowerment developed and conducted by researchers at Vanderbilt University (Bickman, Heflinger, Northrup, Sonnichsen, & Shilling, 1998; Heflinger, Bickman, Northrup, & Sonnichsen, 1997) had a significant effect on two factors considered crucial to increased parent empowerment—increased knowledge of the mental health service system, and mental health services efficacy. Particularly relevant is the work of Taub and colleagues (2001), who found that when families engaged in activities considered to improve family empowerment [as assessed by the Family Empowerment Scale (FES) developed by Koren, DeChillo, & Friesen, 1992], they began to feel empowered over time, and that as the parent’s sense of self-efficacy and control increased, they reported fewer behavioral problems of their child or adolescent.

Further supporting the findings of Taub et al., Graves and Shelton (2007) also used the FES to study the effect of empowerment on child outcomes. The population examined included children with SED at risk of out-of-home placement. Graves and Shelton’s study found that while levels of family empowerment increased, children’s problem behaviors decreased over a one-year period; greater perceived fidelity to family-centered elements of the system of care philosophy were linked to greater positive change in child functioning; greater levels of family empowerment were linked to greater positive change in child functioning; and family empowerment acts as a mediator
between family-centered care and changes in child functioning and also appears to be one important mechanism of change.

Finally, in one of the only studies to examine family driven care using data from the National Evaluation for the CMHI, Osher, Xu, and Allen (2006) found that high engagement by families led to significant improvements in school behavior for their children, including decreases in expulsions, suspensions, and detention referrals, which supports the findings of improved child behavior noted by Taub et al. (2001) and Graves and Shelton (2007).

Because family involvement in evaluation is a federal requirement for systems of care funded through the CMHI, Jivanjee and Robinson (2007) examined the role of families in evaluation and research. Jivanjee and Robinson note, as discussed in Turnbull, Friesen, and Ramirez (1998) and Burke (1998), that family and consumer participation is believed to result in: 1) increased relevance of questions to the needs and concerns of families, 2) improved cultural appropriateness of methods, 3) increased quality and accuracy of data, 4) more accurate interpretations of findings, 5) wider dissemination of findings, and 6) more effective utilization of findings to guide programmatic improvements. Further, Cunningham et al. (2008) note that parental goals may actually differ from goals set by professionals; as a result, when parents are involved in setting goals and assessing outcomes, they are more likely to benefit from goals that they have identified as important to them. Prescott (2001) reports similar research benefits with the inclusion of consumer/survivor/recovering women.

*Values argument.* In addition to research that shows that family involvement leads to positive outcomes for children and families, many would argue that regardless of
outcomes, family involvement in decision making at any level of the system is simply a right that families should have. Over 20 years ago, Dunst and Trivett (1987) made this argument, stating that principles of empowerment provide a value that essentially makes the link to outcomes superfluous. This position is supported by others in the field who argue that involvement of consumers in system level planning and decision making is the ethical thing to do (Croft & Beresford, 1992; Linhorst, Eckert, & Hamilton, 2005; National Association of Social Workers, 2008). The recognized value of families in this process was foundational to the original intent of the federal mandate for family driven care. Over the last several years, this position has become even more broadly shared, and the benefits of family involvement clearly articulated. For example, Huff and Osher (2007), in discussing the impact that families can have on systems change, note that it is critical to have their involvement at this level because families know what works for them; a family’s holistic experience allows a broad perspective of the entire system; families have credibility; families are passionate and persistent; family and youth buy-in are necessary for success; and families, consumers, and youth have the ability to organize.

Regarding direct benefits to families, Graves and Shelton (2007) note that by empowering families to develop possible solutions to problems or needs, professionals are helping to address current issues by assisting the family in developing skills that will help them with long-term problem solving. As family empowerment increases, the family becomes less dependent upon service providers to address challenges they face.

Prescott (2001) highlights the benefits, at both service and system levels, when consumers are integrated into the workforce. She notes that this involvement improves
the quality of services and systems, contributes to systems knowledge, creates customer orientation, positively affects policy development, adds diversity to environmental climates, reduces stigma, provides positive role modeling, promotes increased awareness and education among co-workers, provides knowledge about and linkages to community and alternative resources, and increases client engagement and retention. Finally, it is also important to remember that the value of involving families at all levels of the mental health service system is reflected in mandates within federal programs and has been demanded by family advocacy organizations as they have begun to realize the importance of including family voice (Jivanjee & Robinson, 2007).

In summary, although there is a strong argument for engaging families because of their right to be involved in the decision making process, the lack of empirical data related to empowerment of families at the system level is still troubling for the field of children’s mental health in an era of data-based decision making and accountability. Is it due to difficulty in creating a causal link between family involvement and broader system outcomes such as out-of-home placement or reduction in costs? Is it because the family driven care movement is still in its formative years? Is it due to the limited number of measures available to assess family driven care? Continuing efforts by advocacy groups such as the FFCMH and NAMI are attempting to address this issue through workgroups and the development of tools to assess family driven care. However, each of these questions should be answered to continue to move toward full inclusion of families.

**Challenges to engaging families.** The section above provides a rationale for the increased role of families in decision making in children’s mental health services at all levels. However, there are many challenges that must be addressed during such a
significant transformation in the service system. As described earlier in this review of the literature, there continues to be a stigma surrounding parents as causal agents for the emotional and behavioral challenges of their children. This negative perception—whether experienced at the individual treatment or system level—clearly creates a barrier for a parent-professional partnership of mutual respect, honest communication, and effective problem solving. In fact, when describing treatment alliances between parents and professionals, Alexander and Dore (1999) highlight the negative beliefs that clinicians have about parents’ responsibility for their child’s problems as a significant barrier to treatment alliance.

Some hallmarks of family driven care at the system level include the involvement of families on governing and policy-making boards and during evaluation activities. Cooper et al. (2008) highlight challenges still faced in involving families in state policy: inconsistency in the inclusion of families, overall weak commitment to families, poor tools to create and sustain family engagement, and lack of power to backup the commitments made to families. Osher, Penn, and Spencer (2008) echo some of these same challenges. In describing pitfalls to avoid in family driven care, they note that on governance boards, families historically have had “token” representation, in which they are not truly respected as equals within the decision making process. In addition, there may be only one family member present, who is expected to represent the voice of all family members in the community. Often, families continue to be intimidated by the number of professionals within these meetings (especially if there is only one family representative), the family representative may lack adequate or accurate information (as
found by Osher, Xu, & Allen, 2006), and he or she may not be willing to express an opinion.

Other researchers note similar challenges specific to families as evaluators, such as disingenuous inclusion of families during decision making (Pullmann, 2009), concerns over role ambiguity and power shifts, differences in evaluators’ and family members’ goals and perspectives, and perceived compromises in the rigor of the research (Jivanjee & Robinson, 2007). Finally, training families to become active members of the research team often includes high project costs and increased project time (Jivanjee & Robinson, 2007).

Osher, Penn, and Spencer (2008) address some of the more personal challenges that active family members face. Family representatives often struggle with having to balance the needs of their child with mental health challenges with their responsibilities on committees and governance bodies and as advocates and peer support within the system of care. This includes even the most basic logistical issues such as transportation, childcare, and expenses incurred when they participate in meetings. Finally, when family members have paid positions within the system of care, they sometimes feel caught between advocating for families and representing the interests of their employers.

Duchnowski and Kutash’s (2007) examination of factors that inhibit more active participation of parents in school-related activities strikes a similar cord. For example, they note that parents of children with special needs feel overwhelmed and isolated by lack of information, are intimidated by unequal power, feel blamed and disrespected by school personnel, and have experienced poor school customer service. It is easy to see the similarities faced by parents within the educational setting and the overall system of care.
In summary, this section elucidated some of the challenges related to engaging families, many of which are reflected at all levels of service delivery. There were a couple of common themes. The literature reveals continued challenges in relationship development between families and providers: a continued perception that families are responsible for their child’s mental health issues, a lack of or disingenuous inclusion of families, perceived intimidation of families, and power differentials (whether because families have unequal power or whether providers are reluctant to relinquish power). There were also issues related to communication and information—families needing to receive accurate and adequate information, as well as appropriate training (particularly if they are involved in evaluation). It was also noted that everyday family issues may prevent them from actively engaging—transportation issues, childcare—as well as inflexible work schedules that do not allow participation in meetings held during work hours. All of these are even more challenging for parents raising a child with mental health needs.

Components of successful family driven care. Previous sections of this review address the value of family driven care and acknowledge the challenges in engaging families at all levels of the system. This leads to an examination of what researchers, practitioners, and family members view as important components and strategies for successful family driven care within systems of care. Much of the literature has been written within the last few years. This is reflective of the youth of this movement and the strong need for information.

Osher, Osher, and Blau (2006) offer strategies to ensure that families are involved in decision making within children’s mental health. They include: 1) ensure that meetings
occur at times that are realistic for families to attend; 2) conduct meetings in culturally and linguistically competent environments; 3) ensure that family and youth voices are heard and valued; 4) ensure that families and youth have access to useful, usable, and understandable information and data; 5) provide sound professional expertise to help families make decisions; 6) share power, authority, resources, and responsibility; and 7) construct funding mechanisms to allow families and youth to have choice. These strategies are particularly important, as they have implications for families at all levels of the system of care.

Scheer and Gavazzi (2009) recently examined what promotes family empowerment in behavioral health programs by conducting focus groups with families, parent advocates, and service providers and administrators. They found that parent advocates and mentors played a critical role and that they engaged in a variety of activities with families, from listening and offering support to encouraging family decision-making, to ensuring that overall programming efforts were intended to meet the family's needs. Scheer and Gavazzi note that offering respect, information about their rights, and a sense of voice and choice for families were particularly effective in empowering families. They also found that when advocates were respected and supported in their role within the program, they in turn passed this respect and support along to the families with whom they worked.

Scheer and Gavazzi’s findings were consistent with earlier work of DeChillo, Koren, and Schultze (1994), who found that parent advocates or family mentors were most frequently cited by service providers and program administrators as key components for creating an environment that empowered and engaged families. In
particular, DeChillo and colleagues found four key elements for a successful partnership between families and providers: supportive relationships, practical service arrangements, forthright information exchange, and a flexible and shared approach to gauging failure or success. DeChillo and colleagues note the importance of creating an “environment” that empowers families. This idea is supported by the work of Duchnowski and Kutash (2007), who emphasize the importance of changing the culture to one that creates an effective partnership between professionals and families who have youth with emotional or behavioral challenges. In particular, they note that the culture must change from one of blame, suspicion, mistrust, condescension, frustration, and litigation to one of valuing each other, focusing on strengths, sharing a common vision, pooling resources, having mutual respect and understanding, and advocacy to help strengthen families and the system.

Jivanjee and Robinson (2007) describe strategies related to the important role of families as evaluators within systems of care. They acknowledge the challenges in bringing families into evaluative work, knowing that this is often an unfamiliar area. But they note that families can have a very active role on an evaluation team: as members of advisory groups, assisting in instrument development, interviewing families, arranging focus groups, training other family members, assisting with data analysis and interpretation of results, presenting data at conferences and meetings with local public and mental health officials and community members, and helping with dissemination of findings in written reports.

Taub and colleagues (2001) identify three strategies for promoting family involvement at the system level: provide additional support to parent administered
programs (many of which rely upon volunteers), provide innovative training on professional-parent partnerships for both professionals and family members, and encourage their participation in research. Although lacking in specificity, these recommendations provide an overview of important components for successful family driven care.

The research of Lazear and Anderson (2008) support Taub et al.’s assertion that parent administered programs need support. Lazear and Anderson found six key elements of systems of care that have strong family voice and family driven care: 1) targeted resources to support and sustain the development and growth of a family-run organization; 2) a family-run organization that is actively encouraged and supported in seeking to recruit and engage diverse family and youth leaders; 3) a family-run organization that is encouraged and supported to help family members and youth operate in peer support roles; 4) a family-run organization that plays a key role in ensuring families and youth have access to needed quality services; 5) a family-run organization that plays a role in changing the traditional relationships between families and government agencies, providers, and advocacy organizations in order to strengthen policy commitment and service delivery, and 6) a family-run organization that is supported and encouraged to engage families and youth in changing policy.

The importance of supporting and partnering with a family-run organization within a system of care is also emphasized by, Osher, Penn, and Spencer (2008) who note that strategies to strengthen this partnership include: building relationships among the family organization, providers and policy-makers; mentoring and educating family members in administrative positions; ensuring their autonomy; sharing power; providing
in-kind support and co-location; and working toward having family organizations or chapters within close geographic proximity to ensure development of local relationships. These strategies are actually about developing a culture in which family organizations are welcomed and respected within the system of care. It is important to consider the impact that changing the organizational culture would have on family driven care.

For communities currently funded through the CMHI, the Technical Assistance Partnership’s *Crosswalk to Implementing Your Cooperative Agreement* also offers some resources and strategies for engaging families within the system of care effort, including offering training on family driven care, creating structures that have families effectively involved in service planning as well as development and implementation of a continuum of services, having diverse family participation, hiring families as leaders in the system, and partnering with the family organization in the community (Technical Assistance Partnership, 2009).

Review of the literature reveals that many of these strategies are specific to system partners strengthening relationships with family organizations. Even an examination of literature around engagement of *individual* families often shows a theme of peer-to-peer support, family support groups, and family advocacy. This substantiates the emphasis that the field of children’s mental health has placed on having an active family organization. This is reflected not only in the strengthening of family organizations and their networks across the country but also in federal and state funding that is provided for family organizations, the prominent role they play in policy development, and funding requirements for system of care communities in which they
must demonstrate a partnership with a local family-run organization or provide a plan for developing one within the first year of funding.

**The need for a framework for family driven care.** A comprehensive review of the literature around family involvement in children’s mental health confirmed that although current literature offers some strategies for implementing family driven care within the system, there is no framework or consistent strategy for planners and implementers to successfully engage families. Jivanjee and Robinson clearly articulate the field’s predicament:

While there are clear requirements for family participation from these federal-level policy statements, there has been little guidance to communities about how to translate the broad requirements into specific practices at the local level. Communities have therefore developed their own unique responses to local social, political, and cultural conditions (Jivanjee & Robinson, 2007, p. 370)

Jivanjee and Robinson’s position that communities would benefit from further guidance in translating these requirements into specific practices has been supported by practitioners in the field (for example, Baxter, 2010) and even at the federal level (Blau, 2009). In fact, results of the first ever Policy Academy on Family-Driven Care which convened in February of 2009 confirmed that even communities highly committed to engaging families in service planning and decision making have no consensus on how to define or carry out this effort (Blau, 2009). Although researchers and advocates are beginning to shed new light on the role of families and family organizations at the system level, there is much progress to be made.
Empirically-Based Frameworks for Family Driven Care

The purpose of this section of the literature review is twofold: 1) to examine frameworks for empowering stakeholders within organizations and systems, and 2) to develop a framework for implementation of family driven care at the system level based on current literature.

As stated earlier in this literature review, systems of care that are funded through the CMHI have been mandated to work toward family driven care within their systems. This includes activities such as having families involved in system level decision making and evaluation activities as well as requiring that the communities partner with or develop (if not already developed) a local family-run organization. However, system of care planners and implementers are challenged with how to carry out this mandate. A review of the literature on family driven care provides lists of strategies for engaging families, but the literature lacks a visual representation of how these strategies may link together to develop family driven care within a system of care. During the review of the literature, it was clear that terms such as “framework” and “model” are used quite liberally. For the purpose of this dissertation, “framework” is defined as a “hypothetical description of a complex entity or process” (Framework, n.d.). In this case, a framework is aimed to visually represent not only component parts, but also the relationship between the component parts. Empirically-based frameworks for implementing family driven care in children’s mental health are lacking. As a result, a review of frameworks related to family engagement in system level service planning and delivery decisions included not only child but also adult mental health, primary care medicine, education, and consumer involvement in public and non-profit organizations or systems. In addition,
organizational literature related to shared decision making and collective leadership was reviewed to determine the potential contributions to understanding how families might be better integrated into system level service planning and delivery decisions.

Before proceeding to an examination of frameworks, it should be noted that terminology around family driven care varies greatly across disciplines. What is often referred to as “family driven care” within children’s mental health may be referred to as consumer empowerment within the adult mental health and substance abuse systems, patient empowerment within traditional medicine, parent empowerment within education, and stakeholder empowerment or shared leadership in organizational literature—whether in human services/non-profit or for-profit organizations. The literature shows that shared leadership parallels family driven care, as traditional administrators relinquish power and share in decision making with stakeholders. As mentioned within the literature section on family driven care, this willingness to relinquish power is a primary barrier to successful family driven care.

The literature review was conducted using a wide variety of terms while attempting to follow two criteria: 1) focus on the examination of empirically-based frameworks as much as possible, and 2) focus on frameworks that illustrate engagement of families at the system level. Several frameworks that have particular relevance to family driven care will be described, and it should be noted that a number of these frameworks lack an empirical base but contribute enough to the discussion to be included.

**Mental health frameworks.** A review of the children’s mental health literature indicates that although the language of children’s mental health addresses engaging
families in system level service planning and decision making, work to develop empirically-based models for engaging families is only at a preliminary stage. Very few frameworks have both a system level focus and an empirical base. In addition, several “frameworks” do not adhere to the criteria of illustrating component parts and their linkages (for example, Cohen & Lavach, 1995; Linhorst, Eckert, & Hamilton, 2005; McDaid, 2010, Osher, Penn, & Spencer, 2008; Sabin & Daniels, 1999; all of whom offer excellent strategies for family and consumer empowerment).

A framework offered by Hodges, Hernandez, and Nesman (2003) illustrates a developmental framework for family involvement. In Figure 2, the authors identify four developmental stages:

![Diagram](image_url)


The stages of this framework align well with literature around the evolution of families within the mental health service system. The authors emphasize the importance of always being aware of the developmental stage; knowing where the initiative has
reached is critical for accurately assessing success. In addition, if strategies are implemented for a developmental stage beyond where a family currently is, without the tools necessary to carry them forward to more advanced developmental stages, they may be thrust into a situation without the appropriate skills or supports to be successful (Duchnowski & Kutash, 2007).

A program model offered by Mottaghipour and colleagues (2006) includes two major components: a service development component and a family engagement and support component. Figure 3 illustrates that the service development component focuses on strategies to increase the capacity of the mental health providers to work with families of clients with mental illness. Strategies include increasing knowledge and skills to work with these families, increasing organizational support, and developing and ensuring appropriate resources to work with the families. The family engagement and support component focuses on decreasing the burden for these families but includes strategies such as improving linkages for families, increasing knowledge and skills, and increasing support for families.

Although the framework was designed for engagement at the service delivery level, each component could be expanded to the broader system of care and could have more specific strategies around linkages, training, and support at the system level. It should be noted that this model was not developed within the United States mental health service system but could still be directly applied to systems of care.
Veysey and colleagues provide an impressive model of Woman-Centered Growth Potential. This model was developed from research conducted with women who are consumers of mental health services, survivors of trauma, and recovering from substance abuse, and uses a blended theory that combines Maslow’s hierarchy of needs, Herman’s stages of recovery, and the Stone Center’s Relational Theory of women’s recovery (Vesey et al., 2005). This model is particularly remarkable because it captures the transformation of a consumer, who initially needs her most basic needs met to someone who grows into an advocate and supporter (Activism/Altruism) and transitions into someone with overall wellness. Figure 4 illustrates this evolution from recovery to growth and points of intervention along the way, such as developing empowering relations, skill development, and having a valued role.

If this framework is considered within the context of systems of care, each of the intervening points can be viewed as possible shifts in structures, processes, and relationships within the system that support and empower the woman/parent/family. In addition, this framework offers a “recontextualization” component, which, when viewed in terms of systems transformation reflects many critical aspects of family driven care, such as funding and policy changes.

**Frameworks from fields beyond mental health.** An examination of frameworks beyond the mental health field yields a number of frameworks for engaging family members, consumers, and other stakeholders (including employees) in organizational and system level planning and decision making.
Primary care medicine offers frameworks for shared decision making, but these are generally related to patient participation in health decision making with their physicians at the individual treatment level without generalizability to broader organizational or system level partnering (for example, Charles, Gafni, & Whelan, 1999 and McCafferty, Smith, & Wolf, 2010).

In the field of education, advances have been made in engaging families in decision making not only at the individual child and family levels, but in a limited way at the organizational or system levels. Epstein and colleagues (2002) propose six types of parent engagement as well as activities and examples for school personnel and parents. They begin with Type 1: Parenting, which is described as activities that increase families’ understanding of their children’s growth and development. Type 2: Communicating includes bidirectional communication between school and parents to discuss children’s progress. Type 3: Volunteering consists of volunteer activities for the parents within the school, classrooms, or in the community. This type demonstrates a more active engagement by parents, as does Type 4: Learning at Home. Learning at Home includes active participation between parents and children during homework and other curriculum-related activities and decisions. Epstein notes that these types of activities increase teacher-parent and parent-child communication. Type 5: Decision-Making allows parents to be involved in making decisions about school programs, and includes participation on various teams, committees, and organizations throughout the school. The final type is Type 6: Collaborating with the Communities, which includes activities that encourage the cooperation of schools, families, and community groups, organizations, agencies and individuals, and reflects the highest level of involvement of
families. The framework developed by Epstein et al., although not described as a developmental model by the authors, could suggest a logical progression of family engagement within the school and community settings. Developing an illustration of the components of the framework developed by Epstein and colleagues and adding arrows to reflect a proposed progression of stages for the engagement of parents within the school setting allows the reader to consider the variability in which families may be able to engage successfully within the school setting (Figure 5).

![Diagram](image)

Another useful framework is a logic model for district wide family engagement developed by Westmoreland and colleagues for the Harvard Family Research Project (2009), which includes five major components:

- **Goals**, for the children, families, schools, and school districts;
- **Inputs**, which include a variety of elements such as a vision statement, assumptions, and resources;
- **Activities**, categorized by district, school, and individual practice levels;
- **Outcomes**, which are subdivided into short-term, interim, and long-term outcomes and include district/district staff, school/school staff, family or home, and child/student outcomes; and
- **Performance Measures**, which describe both measures of effort (#) and measures of effect (%).

The logic model, in Figure 6, shows potential for considering family driven care at the system level. Its focus on activities and outcomes at all levels (district, school, family and child) translates well to family engagement activities at the system, organization/program, and family levels within a system of care and would offer not only a basic framework but also corresponding strategies.
### Sample Logic Model for a Districtwide Family Engagement Strategy

**(1) Goals**
- Children and youth are better prepared for post-secondary success.
- Family members are wise consumers and active partners in their child’s education.
- Schools are transformed, high-performing, and accountable institutions.
- The school district has a systemic and co-constructed family engagement strategy.

**(2) Inputs**
- Shared vision for family engagement
- Family engagement connected to student learning
- Strategic investments in programming and staff
- Robust communication systems
- Evaluation for accountability and continuous learning

**(3) Activities**

<table>
<thead>
<tr>
<th><strong>Build school capacity</strong></th>
<th><strong>Foster district-wide strategies</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Provide ongoing professional development opportunities for family engagement to all staff</td>
<td>- Align family engagement with district learning goals and standards</td>
</tr>
<tr>
<td>- Hire family and community liaisons</td>
<td>- Create a well-staffed office for family engagement</td>
</tr>
<tr>
<td>- Implement school-based action teams for family engagement</td>
<td>- Include family engagement in classroom, school, and district performance measures</td>
</tr>
<tr>
<td>- Create mechanisms for administrators and educators to share lessons learned</td>
<td><strong>Reach out to and engage families</strong></td>
</tr>
</tbody>
</table>

| - Create feedback loops with families to plan, implement, and assess activities | - Create data systems that collect and share information with families |

**(4) Outcomes**

<table>
<thead>
<tr>
<th><strong>Short-term outcomes</strong></th>
<th><strong>Interim outcomes</strong></th>
<th><strong>Long-term outcomes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Increased awareness about the importance of family engagement (D, S, F)</td>
<td>- Improved home-school communication and family-school staff relationships (S, F)</td>
<td>- Improved work habits and motivation (C)</td>
</tr>
<tr>
<td>- Increased awareness about rights and opportunities for family engagement (D, S, F)</td>
<td>- Better home environment and parenting to support learning (F)</td>
<td>- Increased school attendance (C)</td>
</tr>
<tr>
<td>- Improved attitudes for shared responsibility, role efficacy, and coordination of family engagement (D, S, F)</td>
<td>- Improved parent-child relationships (F, C)</td>
<td>- More enrollment in more challenging courses (C)</td>
</tr>
<tr>
<td>- More knowledge and skills about strategies for family engagement (D, S, F)</td>
<td>- Improved school culture, including trust among staff (S)</td>
<td>- Smoother transitions across schools and grades (C)</td>
</tr>
<tr>
<td>- More knowledge of strategies and resources to support student learning (S, F)</td>
<td>- More participation and use of programs and resources that support student learning (C)</td>
<td>- Increased student achievement (C)</td>
</tr>
<tr>
<td>- Better understanding of child academic progress, strengths, and weaknesses (S, F)</td>
<td></td>
<td>- Decreased likelihood to engage in high risk behaviors (C)</td>
</tr>
</tbody>
</table>

**(5) Performance Measures**

<table>
<thead>
<tr>
<th><strong>Measures of effort (selected examples)</strong></th>
<th><strong>Measures of effect (selected examples)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td># of hours of professional development/training provided</td>
<td>% of participants reporting that they gained new skills to enable better family engagement</td>
</tr>
<tr>
<td># of participants that attended PD/training events</td>
<td>% of family members reporting more literacy activity at home</td>
</tr>
<tr>
<td># of hits to district family involvement website</td>
<td>% increase in attendance at parent-teacher conferences</td>
</tr>
<tr>
<td># of new school and district family engagement hires</td>
<td>Changes in school/district policies that promote family engagement</td>
</tr>
<tr>
<td>% of participants reporting that trainings were useful</td>
<td>% change in student attendance at participating schools</td>
</tr>
<tr>
<td>% of schools in compliance with all Title I requirements</td>
<td></td>
</tr>
</tbody>
</table>

---

Examination of the literature yields some interesting frameworks for shared leadership and decision making in public and non-profit human service organizations. Although not a traditional framework, Cho and Faerman (2009) examined the constructs of structural empowerment and psychological empowerment in public organizations in an attempt to better measure these concepts and showed linkages between these constructs and measurable dimensions. They conducted a confirmatory factor analysis (CFA) that showed: a) that psychological and structural empowerment are two distinct concepts; b) that there are strong linkages between structural empowerment and the dimensions of participatory decision making, feedback on performance, and delegation; and c) that there are strong linkages between psychological empowerment and self determination and (to slightly lesser degrees) impact, competence, and meaning. Germaine to the overall discussion of frameworks for family driven care is the suggestion that there are two types of empowerment that may impact the success or failure of family driven care.

In addition, Saxton (2005) offers a framework that depicts the depth of stakeholder participation in decision making. His framework reflects the level of stakeholder participation on a continuum. The framework illustrates that as the level of stakeholder participation increases, the role of the participant changes. His framework, which reflects five different levels of increasing participation begins with No Consultation, where the role of stakeholders is that of a Subject. In children’s mental health, this level would be comparable to the notion of families simply as recipients of care. On the opposite end of the spectrum, Saxton describes the most engaged level, in which stakeholder participation is the Ability to select, implement, evaluate, and change alternatives” (Saxton, 2005, p. 36) and the role of the stakeholder as Decision Maker. In
children’s mental health, this is reflective of family driven care, in which families are decision making partners within the system. This framework is interesting to examine in the context of family driven care, as it offers not only more detail than other frameworks but also characteristics or activities that are measurable. There are a number of frameworks that offer or allude to a continuum of engagement. Although ideally the goal is toward family driven care, in reality many systems of care as well as families are not at the highest levels of engagement and need to work through a process of increased participation of families. Other frameworks in public and non-profit human service organizations offer processes for gathering stakeholder perspectives but do not focus on stakeholders as equal partners (for example, Holosko, Leslie, & Cassano, 2001).

Finally, there is an expansive collection of frameworks for shared decision making within the literature related to organizational leadership in more traditional for-profit settings, some more applicable than others. Friedrich et al. (2009) offer a strong framework of collective leadership; however, when examined in detail, the framework illustrates what collective leadership “looks like” within an organization but not how to achieve it. Other models of shared leadership tend to focus on the development of teams and empowerment of the team members (i.e., meso-level) while maintaining traditional leadership at the macro level (for example, Bligh, Pearce, & Kohles, 2006; Cox, Pearce, & Perry, 2003).

The final framework to be examined reflects an empowerment process developed by Conger and Kanungo (1988). Figure 7 illustrates five stages in the process and provides strategies to move toward the empowerment of employees within an organization. What is particularly relevant within this framework is that although each
section is viewed as a stage, they are quite similar to components of a theory of change logic model in that there is first a context, in this case one that leads to a state of powerlessness (Stage 1), then strategies and information to move employees toward empowerment (Stages 2 and 3). Stages 4 and 5 actually reflect short and long-term outcomes.


All of the frameworks described within this chapter establish a foundation for considering how systems can empower stakeholders in macro-level decision making. These frameworks provide snapshots of continua of family involvement, organizational and system level activities that promote stakeholder involvement, and even a framework
that focuses on the transformation of a consumer into one who actualizes wellbeing. Although these frameworks present different perspectives, they all offer components that have the potential to contribute to a framework for implementing family driven care at the system level. A new framework for implementing family driven care will be described below.

**Proposed Framework for Implementing System Level Family Driven Care**

The process used to develop a new framework for implementing family driven care is based on Johnson’s *meta-modeling* technique (1998). Johnson defines meta-modeling as “developing models from models” (Johnson, 1998, p. 94) and describes it as an inductive, theory-building approach using a specific data source. Within this process, the researcher develops an implicit theoretical model based on the literature, examines already developed (explicit) models, and incorporates features of both into a mega-model. Johnson notes that the researcher must always be attentive to components that may be missing from either model and need to be incorporated, and emphasizes that this is a "mixture of empiricism and rationalism" (Johnson, 1998, p. 94).

The family driven care movement is still in its infancy. Its youth limits the amount of literature available to develop the initial implicit theoretical framework. As a result, Johnson’s approach has been adapted by combining implicit and explicit components to develop the framework. This framework will then be examined within the context of data from *Case Studies of System Implementation* for further refinement.

Figure 8 illustrates a preliminary framework for implementing family driven care. It reflects broad categories of components that emerged from the literature and their linkages. The broader categories of *context, assessment, strategies, and outcomes* are
represented by headings in all capital letters. The context provides a background and foundation for activities that occur within the system. Outcomes should ultimately guide activities within the system; however, assessment of progress toward family driven care guides the strategies that are implemented and should be an ongoing process, which is reflected by an assessment loop within the framework.

**Context.**

**Shared vision.** The framework, when examined from left to right, begins with a shared vision for family driven care across all system partners and is the foundation for a system that includes families at all levels. This vision, if not shared across partners, may result in families who are very active in decision making within one or two agencies but are prevented from fully engaging as equal members on governing boards, councils, or planning committees; contrary to the intent of family driven care. This shared vision leads to activities of system leaders that foster a culture of inclusion of families and a meaningful partnership with family organizations.

**System leaders.** System leaders who genuinely value families as partners within the system work to build a system of inclusion. Influences upon these leaders are many and may be intrinsic (e.g., a strongly held value that involving families is the right thing to do, or the realization that the benefits when sharing power to strengthen the system and better serve children and families far outweigh the costs), or extrinsic (e.g., legislative mandates, litigation, or other political pressures, the receipt or withholding of funding). The important point is that system leaders have the capacity to strongly influence other contextual factors that appear essential to the successful integration of families into the system.
Figure 8. Framework 1: A Literature-based Framework for Implementing Family Driven Care
**Culture of inclusion.** Fostering a culture of inclusion consists of creating an environment in which families feel welcome and their voices are heard and valued. There is an emphasis on mutual respect, team building, and partnership in decision making and problem solving. The literature reflects this cultural shift as foundational for successful partnerships between parents and traditional professionals.

**Partnership with family organizations.** This partnership occurs with organizations that provide support, training, advocacy, and mentorship to families of youth with SED. The literature reflects not only a particularly strong emphasis on partnerships with family organizations, but also that these organizations are often well-organized, autonomous, influential in policy-making activities, are located or have strong ties within the local community, and are “present” within the system (i.e., engaged in mentoring and peer-to-peer support and education of families within the system).

**Stakeholder commitment.** Stakeholder commitment is included within the framework to reflect activity that translates these contextual components into activities that move the system forward.

**Assessment.** The assessment component of the framework reflects the importance of assessing where the system is in regard to developing family driven care as well as gauging where families are in the empowerment process. There is a strong need for tools that assess system progress toward family driven care as well as updated instruments to assess family empowerment, as systems of care continue to use an instrument that is almost 20 years old and assesses empowerment of families at the individual, service system, and community levels (FES; Koren, DeChillo, & Friesen, 1992), not solely with a focus on the system level. Assessment is also critical to determine where to focus
efforts within the system. For example, a system of care may have strong training for families and providers specific to parent-professional partnerships but may be very weak in other areas such as sharing data and information. Continually assessing progress toward family driven care and implementing system strategies that move the system toward the goal of full inclusion of families at all levels of the system are critical to the process. The Assessment Loop is intended to represent this ongoing activity.

**Strategies.** The strategy components of the framework are more straightforward than the previous components of the framework and are well documented within the literature. These include a variety of activities that are briefly described below.

**Training.** Training for families and providers includes topics such as developing parent-professional partnerships, leadership, and evaluation methods and skills.

**Advocacy, mentoring and support.** The literature strongly emphasizes the inclusion of advocacy, peer-to-peer mentoring, education, and support as core components for full family partnership. These may be carried out by a family organization or may be independent from a formal family organization; but they are likely to occur at a number of levels within the system.

**Membership and authority.** Membership and authority includes having involvement in planning, decision making authority, and shared responsibility for outcomes, to name a few examples. This membership may occur on governing boards, decision making councils, planning committees, and evaluation teams. The literature reflects the importance of membership that is genuine (i.e., avoids “tokenism”) and consideration for logistical challenges of families to ensure active participation.
**Strategic investment of resources.** The literature shows that these resources may be linked to things such as training, sustainable employment opportunities, or flexible funds to ensure families are able to attend meetings and participate regularly.

**Communication.** The literature reflected that bidirectional communication between parents and system providers encourages joint planning and problem solving.

**Access to and utilization of information.** The literature review showed an emphasis on sharing information with families. Families within systems of care often feel isolated by lack of or inadequate information, and the literature reflected the importance of families receiving complete and accurate information for planning and informed decision making at all levels of the system.

**Outcomes.** The outcome sought by systems of care implementing this framework is that of families as equal partners in decision making at all levels of the system. As such, the definition of family driven care is included within the outcomes section of the framework. Measurable objectives can be outlined and linked to strategies that move the system toward family driven care. For instance, training opportunities for families may be expanded to address specific topics around leadership, team building, conflict resolution, and evaluation methods. Progress can be assessed by examining things such as the number and availability of training opportunities, number of participants, and assessments of the course and participant skills, to name a few. However, this is only one small component. Regular assessment of a variety of strategies and progress toward family driven care is critical, and is reflected in the assessment loop.

The above discussion is intended to capture components that appear core to implementing family driven care as well as linkages between these components, based on
current literature. This preliminary framework is aimed to reflect a developmental progression from left to right, in that it suggests that a shared vision and leaders who value families as partners may serve as impetuses for activities that drive the system toward the actualization of family driven care. This framework was examined in the context of data from *Case Studies of System Implementation* and was refined based on those data. The second framework was further refined based on data from focus groups conducted with Lead Family Contacts and Principal Investigators and Project Directors of systems of care currently funded through the CMHI.
Chapter Three:

Methods

Introduction

The purpose of this research project was to explicate more fully the roles of families in service planning and delivery decisions through an analysis of the structures, processes, and relationships that support and impede family involvement in system level service planning and delivery decisions in established service systems for children and adolescents with Serious Emotional Disturbance (i.e., systems of care). This study sought to identify the core components and strategies employed by systems of care to successfully engage families as full partners in system level decision making, and to develop a framework that depicts how these processes are carried out.

This chapter will describe the methods used during this research project. The study evolved from research from Case Studies of System Implementation, a research project conducted through the Research and Training Center for Children’s Mental Health (2004). Therefore, a review of the original study begins this chapter. Findings from the study prompted a closer examination of the issue of family driven care, and a secondary analysis of these qualitative data was a critical component of this study. The chapter includes a description of the research design, research questions, data collection, and analysis. This qualitative research study included data collection and analysis that may be considered in terms of a two-phase process. The first phase consisted of data that
were collected from the six system of care communities that participated in the original research study. A description of this process is included, as it describes the rigorous methodology used to collect the data examined during the secondary analysis. The analysis focused on data specific to family involvement in decision making within the systems that participated in the original study. The framework for implementing family driven care, developed from the literature and discussed in Chapter Two, was substantially revised based on an examination of these data.

Phase Two consisted of primary data collection and analysis that occurred during this study. Focus groups were conducted to gather feedback on the revised framework. Data provided by respondents based on their system of care experiences were used to modify the framework. This final framework is described in detail in Chapter Four of this dissertation.

**Research Design**

**Original study.** *Case Studies of System Implementation (CSSI)* was a five-year national study that examined strategies that local communities undertake to implement community-based systems of care (Research and Training Center for Children’s Mental Health, 2004). The purpose of the study was to understand how factors affecting system implementation contribute to the development of well-established systems of care for children with SED and their families. The research project was the first comprehensive study of how systems of care are developed in communities throughout the country. Key points of investigation for the original study included:

- Fundamental mechanisms of system of care development and implementation
• How local context influenced development and implementation of each system of care

• Specific change agents or triggering conditions critical to the system’s development

• How factors that contributed to each system’s development and implementation interacted to produce a well-functioning system of care

• What conditions supported or impeded system development

This qualitative, team-based research study used a multi-site embedded case study design and methodology developed by Yin (2003). This allowed for an examination of the phenomena being studied in each system of care community within real-life context for the purpose of developing a theory around how systems of care are developed. The research team used in-depth data collection from multiple sources (e.g., interviews, observations, and documents), which is viewed as effective in capturing changes in a community over time (Creswell, 1998, 2003; Yin, 2003). The unit of analysis for the original study was the system of care, which included the entire network of child serving agencies that provided services and supports to children and adolescents with SED and their families. Findings from the original study showed components of system development that were shared across all sites, including 1) shared values across system partners, 2) a willingness to change within the system, 3) shared accountability of partners, 4) delegation of authority, 5) strategic use of resources, 6) information based decisions, and 7) family empowerment (Ferreira, Hodges, Kukla-Acevedo, & Mazza, 2008). Data analysis suggested several issues as foci for further study. In particular, a
theme arose related to the role of families in service planning and delivery decisions at various levels of each system, highlighting the need for further examination of this topic.

**Current study.** The current research study examined the roles of families in service planning and delivery decisions through an analysis of the structures, processes, and relationships that support and impede family involvement in system level service planning and decision making in established system of care communities. It built upon the research design and methodology of the original study by conducting a secondary analysis of data collected during the original study. The unit of analysis, the entire system of care, did not change between the original and current studies. Although the topic of the study shifted to how *family driven care* is implemented (versus how overall systems of care are developed and implemented), family driven care is intended to occur across the entire system with the inclusion of all system partners, and was examined as such.

**Research Questions**

To gain a clearer understanding of the role of families in service planning and delivery decision making at the system level, this research project addressed the following 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?

Institutional Review Board (IRB) Approval

Following the successful proposal defense for this study and prior to further data collection and analysis, the researcher submitted the necessary application, protocols, and informed consent documents to the University of South Florida’s Institutional Review Board (IRB). Approval for the study was granted on October 20, 2010.

Phase One

Data collection.

Participating sites. During the original research study, a national nomination process was used to identify potential sites. Criteria for inclusion in the study included having: 1) an identified local population(s) of youth with serious emotional disturbance; 2) clearly identified goals for this population that are consistent with system of care values and principles; 3) active implementation of strategies to achieve these goals; 4) outcome information demonstrating progress toward these goals; and 5) demonstrated sustainability of the system of care over time. Key informant telephone interviews and document review were conducted by the research team to identify sites for inclusion in the study.

A total of six system of care communities participated in the original study, all with varying contexts (e.g., organizational and funding structures, size, demographic variability), in an attempt to maximize differences across systems. Sites 1 and 2 included
a small, single-county system with a strong county government and a multi-county region with a strong state government infrastructure and rural and frontier communities.

These communities were followed by Site 3, a state-wide system that was examined during the study and the only system initiated by a class action legal challenge. This site also reflected significant ethnic and cultural diversity within and across regions of the state, which allowed for an examination of the strategies used to build a system that meets the needs of such a diverse population. Site 4 also reflected significant ethnic and cultural diversity, with half of the county primarily Caucasian and the other half primarily Latino.

Finally, urban communities were examined. The structures of these systems were quite different from each other, with Site 5 having a completely voluntary system of community linkages that form the core structure of the system, and Site 6 reflecting a much more formal structure of cross-agency teams which was administered by a not-for-profit managed care organization.

**Respondents within each site.** Purposive sampling was utilized within each system of care to identify stakeholders to be interviewed for the original study. Criteria included individuals within the system of care (whether working within the system or receiving services) who were able to provide information on system level planning and implementation (versus planning and implementation solely at the individual treatment level). Respondents included broad representation across system partners, and generally included individuals working within the areas of mental health (public and private providers), child welfare, education, juvenile justice/probation, and family organizations. In addition, respondents offered different perspectives from all levels of the system—
policymakers, administrators, program managers, direct-care staff, family members, and youth (over the age of 18). Because titles varied widely across sites, for the purpose of analysis, interview respondents were grouped into the following six categories.

- **Family Member or Advocate**: Individuals representing/supporting the family perspective. This also includes directors of the family organization, who have administrative functions but view their roles as family members or advocates as their predominant roles within the system. These individuals may have paid or unpaid positions within the system. A total of 25 family members/advocates were interviewed; however, some family members chose to be interviewed with another stakeholder—another family member, a service manager, or their child. Thus a total of 20 interviews were conducted with families.

- **Youth**: Youth over the age of 18. A total of 2 interviews were conducted with youth across all sites, one being a joint interview with his parent.

- **Service Provider**: Case/care managers, therapists, psychologists, physicians, nurses, teachers, probation officers, and attorneys. These individuals provided formal services and supports to the child and family within the system. This also included therapists who have some supervisory duties within a program but also carry caseloads. These numbers varied greatly across systems, depending on their organizational structure and the size of their geographic service area. A total of 62 service providers were interviewed across all sites; several in group interviews.
• *Service Manager*: Program managers and directors (middle managers), trainers, special education supervisors who reported to the special education director. A total of 63 service managers were interviewed; several as group interviews.

• *Evaluator*: Internal or external evaluators. May also provide technical assistance (e.g., Universities, consultants), and may have an administrative role. A total of 18 evaluators or technical assistants were interviewed across sites. Some of these with group interviews with 2-3 evaluators in one interview.

• *Administrator or Policy Maker*: System level administrators, funders, policy makers, judges, system partners involved in upper-level decision making. There were a total of 88 interviews conducted with administrators. There were numerous administrative interviews, as the intent of the original study was to examine system development—a highly administrative endeavor.

Some interview respondents had multiple roles within the system. For individuals with multiple roles, they were categorized by their predominant role during the development of their system and their level involvement in decision-making. It should be noted that a total of 258 individuals were interviewed during the original study. However, there were several group interviews, which included multiple respondents. In addition, occasionally one respondent would be interviewed multiple times. Thus the reader will not observe a one-to-one correspondence between the number of transcribed interviews
and the number of respondents. A table detailing the number of respondents by role
within each site is provided in Appendix A.

Procedures and instrumentation.

Document review. The research team began with a review of documents from
each participating site. Documents included items such as state- and local- level reports,
grant information related to the system of care, system and organizational regulations or
guidelines, budget information, evaluation reports, and assessment instruments. These
documents allowed the research team to gain an understanding of system components
such as organizational structure, program components, population of focus, the goal and
intent of the system, evaluation data related to progress toward system goals, system
challenges, and system development within a historical context.

Brainstorming exercise: Factor identification and ratings exercise development.
Prior to onsite data collection, a brainstorming session was conducted with a small group
of stakeholders from each system of care. This usually included administrators of key
system partner agencies, managers, and evaluators, as well other individuals who could
offer a historical perspective of system development. The purpose of the brainstorming
session was for the stakeholders to identify and define factors that were critical to the
successful development and implementation of their local system of care. These factors
were then used as points of discussion during semi-structured interviews during onsite
data collection. They were also validated by interview participants within each system via
a factor ratings exercise in which they were asked for feedback on each identified
factor—recommended changes to the definition as well as ratings on the importance of
each factor, ease of implementing the factor, and success in implementing the factor within their system of care.

*Semi-structured interviews.* During each week-long site visit, the research team conducted semi-structured interviews, direct observations, and continued document review to gain further understanding of how each system of care developed. The protocol for semi-structured interviews included questions related to the historical development of the system, locally identified implementation factors, goals and strategies of the system, communication activities, strengths and challenges for system development, and sustainability efforts. The research team generally had three to four researchers in the field for onsite data collection. All team members were trained in administration of the semi-structured interview protocol as well as how to complete direct observations and field notes. Three of the four core research team members conducted data collection and analysis throughout the five-year research study, providing consistency throughout the project. New team members were trained prior to onsite data collection and analysis. The complete interview protocol is available in Appendix B.

*Direct observations.* The research team also conducted direct observations of naturally occurring meetings within each system. These included interagency meetings such as system of care planning meetings and system level placement meetings as well as child and family team meetings. A basic observation protocol was used in which the researcher noted the meeting participants (with a particular focus on the participant’s role within the system), the observations, and researcher comments, all of which were clearly distinguished from each other.
Although a preliminary interview and observation schedule was developed before onsite data collection, the research team also scheduled and conducted additional interviews while on site. These additional interviews were determined by the research team as it identified potential gaps in data or underrepresentation of particular groups of individuals (e.g., a desire for more family interviews or more interviews from individuals within Juvenile Justice). This was done by brainstorming with lead contacts at each site and using a snowball technique during interviews, asking respondents for recommendations for other individuals to interview.

**Exploring the role of families during original data collection.** Because the interviews were semi-structured, the interview process allowed for exploration of areas in which the respondent had expertise or a particular perspective. For example, when questions were asked such as “How have stakeholders been involved in implementation of your system of care?” respondents working within the family organization, family members, youth, or employees who had faced similar challenges with their own families were often able to provide a more substantive response to this question than other system stakeholders. This was then explored in more detail by the interviewer as he/she asked additional probes to gather further information. In short, the roles and experiences of individuals within the system helped to guide the interviews. In addition, respondents were asked several questions specific to the implementation factors that were identified during the brainstorming process. These included questions about the types of factors or strategies that are most used, factors or strategies that have most affected implementation of the system, and how they link with other factors. Several sites identified factors related to family involvement within the system. For example, sites identified “Family Voice,”
“Family and Youth Participation,” “Family, Youth, Community Partnerships,” and “Family and Youth Movement” as important factors. This allowed for a rich discussion of the role of families within each site.

In addition to exploring the role of families during the interview process, the research team’s conduct of observations within the system yielded data related to the level of involvement of families within system-level planning meetings. Ratings exercises provided an opportunity for respondents to rate the system on factors related to family involvement (if a factor related to family involvement had been identified as critical). Finally, system documents provided a way for the research team to examine the role of families in activities such as strategic planning, policy-making, funding decisions, and evaluation.

**Data analysis.**

**Qualitative secondary analysis.** The original research study used a team-based approach to analyze data. Across study sites, large amounts of data were collected for the purpose of gaining in-depth understanding of the structures, processes, and relationships related to local system development. However, as described above, these data yielded a great deal of information related to the role of families within each system. This dissertation used qualitative secondary analysis (QSA) to more closely examine the role of families within systems of care. Heaton (2004) notes that using QSA to examine additional research questions is widely accepted in the field, and defines a “supplementary analysis” as a secondary analysis that is “a more in-depth investigation of an emergent issue or aspect of the data which was not considered or fully addressed in the primary study” (Heaton, 2004, p. 38). She also notes that it is desirable for QSAs to be
conducted by researchers who were members of the original research team. The analysis of qualitative secondary data is often viewed as a process that is underutilized in the qualitative research community and is receiving heightened attention. The increase in QSA is largely based on an expanding recognition of the value of archival data as well as improved methods for storing and sharing qualitative data (Cisneros Puebla, Mruck, & Roth, 2005; Gladstone, Volpe, & Bydell, 2007, Heaton, 2004).

**Methodological issues in using a secondary data set.** Methodological issues while using QSA are generally sorted into three main categories: accessibility, quality, and suitability (Heaton, 2004). For this study, *accessibility* issues were non-existent, as the researcher was a core team member of the original study and was responsible for storage and organization of all data. More importantly, authorization to conduct continued analyses of these data had previously been granted by the University of South Florida’s Institutional Review Board and the sites who participated in the original study.

Concerns of *quality* often include issues such as whether or not there is a complete dataset, if data are fully and accurately recorded, whether the data have been modified, and whether the original study methodology was rigorous (Heaton, 2004). The research methodology of the original study, which used a case study design, ethnographic methods, and team-based data collection and analysis, was described previously in this chapter. Digital files of approximately 700 items of data were created, organized, and stored by the research team throughout the original five-year research project. The research team’s process for storing these interview transcriptions and notes, observation notes, documents and ratings data are described later in this chapter.
Finally, suitability must be assessed. Heaton (2004) emphasizes that the data must be a good “fit” for the purpose of the proposed research and there must be sufficient data to address the proposed questions. Earlier in this chapter, the researcher touched upon ways in which the concept of family involvement presented itself during data collection and how it was further explored by the research team. As a core member of the original team, this researcher was quite familiar with the data, having analyzed it during the original study and identified the theme of family driven care as one needing further exploration. Table 1 describes the types of original data analyzed during the current research project as well as the initial purpose for collection of the data.

Table 1

Case Studies of System Implementation Data

<table>
<thead>
<tr>
<th>Data Collection and Purpose</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Document review: State- and local- level materials; grant information; regulations or guidelines; budget justifications; monitoring, annual, and evaluation reports; assessment instruments, maps and graphs: Provide organization level data related to goal and intent of system, system implementation, and system of care development in a historical context. Triangulated with interviews and observations</td>
<td>307 documents</td>
</tr>
<tr>
<td>Semi-structured Interviews: Provide individual perspectives regarding factors that have contributed to system development (A total of 258 respondents within 209 interviews)</td>
<td>209 transcribed interviews</td>
</tr>
<tr>
<td>Direct Observation: Used to confirm or disconfirm the presence of identified implementation factors</td>
<td>41 sets of observation notes</td>
</tr>
<tr>
<td>Ratings Exercises: Establish different perspectives on definition, effectiveness, and difficulty in implementing identified factors</td>
<td>113 ratings exercises</td>
</tr>
</tbody>
</table>
**Triangulation.** An important component of qualitative research is ensuring that findings are consistent across all data sources. This process of creating redundancy, or triangulation (Denzin, 1978), is defined by LeCompte and Schensul (1999a) as “confirming or cross-checking the accuracy of data obtained from one source with data collected from other, different sources” (p. 131). Triangulation should be considered during the processes of both data collection and analysis. This includes triangulation of investigators and data. Triangulation of investigators (Denzin, 1978) refers to the engagement of multiple researchers within the same study. The original research study used a team-based approach for data collection and analysis, and this approach was replicated for the QSA as well as data collection and analysis during focus groups.

Triangulation of data (Denzin, 1978) ensures that information from one source (e.g., interviews) is substantiated by other sources, such as observations and written documents. Four sources of data (see Table 1) were included during this research analysis. As LeCompte and Schensul (1999a) note, the triangulation that results from multiple sources creates more credible research results and is critical to the validity and reliability of qualitative research. Semi-structured interviews offer information based on the perspective of the individual being interviewed, and naturally, individuals have varying perceptions based upon history, experiences, and roles within the system. Triangulation of data from other sources such as observation notes and documents allowed the research team a way to confirm findings from other data or to identify contraindications or inconsistencies across data and further explore these inconsistencies. An example during this analysis was a strategic planning retreat in Site 4, in which it was determined that families would be added to membership on an interagency placement
committee. However, minutes from the meeting did not reflect the addition of the family representation.

During the analysis process, it was important to consider triangulation (the convergence of perspectives) of respondents, and it should be noted that even with rigorous methodology, this convergence does not always occur. For example, researchers must be sensitive to the fact that respondents who are family members may consistently identify barriers to family driven care that are different from those identified by administrators. This does not reflect methodological flaws but rather a significant finding that individuals with different roles within the system may have different perspectives. Surprisingly, interview data were quite consistent across respondents. One example of an inconsistency occurred during a group interview with family members within Site 3, in which one family member with many years of experience within the system noted a significant improvement in how members of the family organization are treated by providers, whereas another respondent with fewer years of experience could not support this position. This is not necessarily a contradiction but simply someone with a different frame of reference. More often, the research team noted that some respondents were more outspoken and appeared to have less concern about making unpopular statements during interviews. These were not contractions but rather additional information not provided by other respondents.

**Organizing a large dataset.** In order to organize the approximately 700 data items that were examined during the secondary analysis, digital files were created and stored on a share drive within the College of Behavioral and Community Sciences (BCS). It is important to note that because data collected during the original research study were not
specific client data but rather information about the overall system’s development, IRB approval for the original study did not require de-identification of data, but instead assurance that the data would be secured and only accessible to authorized team members and the IRB. Regardless, for the purpose of this secondary analysis, respondent information on interview data was de-identified to ensure confidentiality of respondents. While naming transcripts, codes for respondents were developed to ensure confidentiality of data while at the same time maintaining the ability to re-identify data if needed to organize the data in a different way (e.g., if it became necessary to examine whether a respondent had a different perspective based on his/her number of years working within the system). The naming convention for an interview transcript for an administrator in, for example, Hillsborough County, FL, would read: HC_## assigned to respondent_Adm_interview date_researcher initials (e.g., HC_160_Adm_062007SH). For the purpose of reporting results within this dissertation, participant sites are identified simply by a site number.

Participants were also de-identified on observation notes; the notes included the study site and name of the meeting. Because the documents collected on site are public record, there was no need to de-identify these data in any way.

All files were imported into ATLAS.ti qualitative data analysis software (ATLAS.ti, 1993-2010) for data reduction and theme identification. ATLAS.ti allows the research team to organize, code, and share the large dataset more efficiently. Hermeneutic Units (HUs), which provide the data structure for a project within ATLAS.ti hold all data for the analysis. The HU (in this case titled Family Driven Care Secondary Analysis) serves as one large file that contains all of the data and, when stored on a share
drive, enables all research team members access to the same file (i.e., HU) during analysis. The files, stored on the BCS share drive, are supported by information technology staff at the University of South Florida. Researchers’ personal computers are connected to the Windows server network, which manages the storage of data. In addition, the server provides a high level of security to protect all research data within the College.

Data analysis. For organizational purposes, data analysis consisted of three distinct steps: 1) data reduction and 2) codebook development and refinement, and 3) coding and identification of themes. These are described below.

Data reduction. A data reduction process was conducted, for the purpose of selecting, focusing, simplifying, and abstracting data (Miles & Huberman, 1994) relevant to family involvement within each system of care. Although the research questions for Case Studies of System Implementation were not specific to family involvement, the strong presence of families in system development and implementation activities emerged as a theme during the initial analyses of the study data. The original analysis, during which this theme strongly emerged, suggested that data reduction would yield enough data to examine research aims related to family involvement.

One of the challenges of data reduction is the risk of unintentionally oversimplifying or distorting data (Miles & Huberman, 1994). LeCompte and Schensul (1999b) support this argument, noting that codes must be kept at a low level of inference, particularly during the early stages of coding. However for the purpose of this reduction, the use of basic words such as “family” or “parent” proved to be ineffective, as almost all interview respondents spoke of families/parents and youth within their interviews.
because these individuals were served within the system of care. As a result, pre-
identified codes related to family and consumer involvement within these systems
included terms such as family/parent involvement, family/parent driven, family/parent
partner, family/parent advocate/advocacy, family/parent empowerment, family focused,
family voice, and variations of these words. The terms family organization and
Federation of Families were also coded.

Data reduction was initially conducted using ATLAS.ti’s auto-coding tool. Auto-
coding is often viewed as effective for coding passages of text using key words and
phrases as selected codes, quickly identifying and clustering passages associated with a
particular concept. Codes for terms such as those described above were developed and
auto-coded. The data reduction process also included a random check of documents that
were not sorted into the final dataset to ensure that exclusion was appropriate. It was
determined that approximately one-third of the documents that were originally excluded
during the auto-coding process should have been included in the final dataset. As a result,
all documents were manually reviewed for inclusion. This was completed independently
by two members of the research team. Team members discussed each document for
which there was lack of agreement (approximately 20 out of the 471 documents that were
hand-coded by the two team members) and a team determination was made as to whether
to include it during data analysis, including any of which consensus was not reached
(erring on the side of inclusion). These data reduction activities reduced the data
considerably, to 403 items.

Auto-coding was ineffective for a few reasons. First, speech patterns of
respondents do not always lend themselves to the word combinations listed above, and
the auto-coding feature codes words or phrases literally. For example, the phrase “We feel that empowering of families is an important aspect of our system” was not auto-coded for “family empowerment.” even though this was the intent. In addition, particular communities used phrases that are not commonly used in systems of care. For instance, one site spoke of “family centered” services, while all others spoke of “family focused,” “family driven,” “family engaged,” etc. This phrase would not have been identified without a manual examination of the documents from that particular site. Even more importantly, auto-coding picked up limited interviews with family members and youth and few documents that related to the family organizations; this likely occurred because families and youth often do not use the terminology professionals have come to associate with family involvement within systems of care. They speak of their experiences but do not use phrases like “family driven,” or “family empowered.” This is a critical point, and an important lesson learned.

All sets of notes from direct observations were not part of data reduction and were all included in the final dataset for analysis. It was determined prior to data reduction that these would need to be hand-coded to ensure the identification of themes that may be embedded in interactions or other group dynamics; these might not otherwise be detected while coding for specific terms.

*Codebook development and refinement.* Systematic coding of text is a key element in qualitative data analysis (Miles & Huberman, 1994; Strauss & Corbin, 1990), and these codes represent the underlying assumptions of the analysis. After data were reduced, a codebook was developed. Based on the work of Guest and MacQueen (2008) and Miles and Huberman (1994), the codebook included five components for each code:
1) code name, 2) brief (1 line) definition, 3) full definition of inclusion criteria, 4) full definition of exclusion criteria, and 5) an example of a passage that illustrates how the code may be presented within the text. Codes were developed related to structures, processes, and relationships that serve to facilitate or impede the involvement of families in service planning and decision making at the system level. The team also considered that systems may have developed structures, processes, or relationships to increase family involvement that neither facilitated nor impeded family involvement. Thus a “Neutral” code was also developed, but ultimately was not particularly relevant and minimally used.

Although these codes were identified and defined a priori, the research team modified the codebook to add the code “Value” early in the coding process. Discussions of values and beliefs related to families as partners within the systems surfaced regularly during interviews. As a result, this code was added to the codebook and previously coded documents were re-coded for Values. Codes used during this analysis and definitions of each code are described in Table 2. The complete codebook is included as Appendix C.

Table 2

*Definitions of Initial Codes*

<table>
<thead>
<tr>
<th>Structures: Specified roles, responsibilities, and authorities that denote organizational boundaries and enable an organization to perform its functions</th>
<th>Facilitators</th>
<th>Impediments</th>
<th>Neither (Neutral)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structures that facilitate meaningful involvement of families at all levels of the system</td>
<td>Structures within the system that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
<td>Lack of structures that facilitate meaningful involvement of families or structures within the system that create barriers to involving families at all levels of the system</td>
<td>Structures within the system that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
</tr>
<tr>
<td><strong>Processes: Methods and procedures for carrying out organizational activities and often involving sequences or sets of interrelated activities that enable an organization to perform its functions</strong></td>
<td><strong>Facilitators</strong></td>
<td><strong>Impediments</strong></td>
<td><strong>Neither (Neutral)</strong></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Processes/activities that are occurring within the system that facilitate meaningful involvement of families at all levels of the system</td>
<td>Lack of evidence of processes that facilitate meaningful involvement of families, or processes occurring within the system of care that create barriers to involving families at all levels of the system</td>
<td>Processes within the system that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Relationships: Trust-based links creating connectedness across people and organizations</strong></th>
<th><strong>Facilitators</strong></th>
<th><strong>Impediments</strong></th>
<th><strong>Neither (Neutral)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships among system stakeholders that facilitate meaningful involvement of families at all levels of the system</td>
<td>Lack of evidence of relationships that have developed across system stakeholders that facilitate meaningful involvement of families, or relationships across system stakeholders that create barriers to involving families at all levels of the system</td>
<td>Relationships among system stakeholders that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Values: An ideal accepted by an individual or group</strong></th>
<th><strong>Facilitators</strong></th>
<th><strong>Impediments</strong></th>
<th><strong>Neither (Neutral)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>The ideal accepted by an individual or group within the system that families should be full partners within the system of care</td>
<td>Lack of evidence of the shared value of families as partners within the system, or conflicting values that create a barrier to involving families as full partners at all levels of the system</td>
<td>Not defined and not used</td>
<td></td>
</tr>
</tbody>
</table>
All team members were involved in codebook development and refinement to ensure a clear understanding and consistent application of the codes. This included training to accurately code using the developed codebook and regular meetings to discuss the coding process, progress, challenges, and questions regarding inclusion and exclusion criteria.

Coding and identification of themes. Team-based qualitative research is an approach that incorporates multiple data sources and triangulation of not only data but also researchers. This approach requires data to be coded individually by multiple team members. Codes are then compared and discussed regularly, the coding system/scheme is refined, and intercoder agreement is established (Bebbe, 2001; Guest & MacQueen, 2008; LeCompte & Schensul, 1999a; Silverman, Ricci, & Gunter, 1990). This project included the Principal Investigator and two additional team members to assist in data analysis during the QSA as well as analysis of focus group data in Phase Two.

After data were reduced and the initial codebook developed, data were coded by the team for the purpose of theme and pattern identification. Coding was conducted by team members individually using ATLAS.ti software. Each coder was assigned his own set of codes and these were filtered during analysis so each team member could only view his sets of codes while assigning codes to quotes. This was done to avoid unintended influence by other coders during the coding process. These codes were then unfiltered to show all codes assigned by all team members during team discussion and debriefing. Team members frequently used the memo feature in ATLAS.ti to explain why particularly elaborate quotes were coded a certain way, and this created even more
consistency across the team. The team began by coding all interviews across participating sites. The team then coded observation notes, documents, and ratings exercises.

*Reliability and validity.* Intercoder agreement (also referred to as intercoder reliability) among research team members occurred with the use of a codebook, regularly scheduled meetings to discuss coding, the use of memos within ATLAS.ti, and periodically checking coding agreement. This was done by having multiple team members code the same section of text and compare results. During the coding of the same text, where inconsistencies were found, the team discussed these inconsistencies to clarify and reach agreement about the codes for those particular sections of text. Early in the coding process, the team met daily or twice weekly to compare coding. The team aimed for intercoder agreement of 85% or higher, as recommended by Guest and MacQueen (2008). This was determined by using the following formula as recommended by Miles and Huberman (1994):

\[
\text{Reliability} = \frac{\text{total number of agreements}}{\text{total number of agreements} + \text{disagreements}}
\]

As expected, intercoder agreement was fairly low at the beginning of the process (approximately 60%) but greatly improved as coding continued, to approximately 80% during random checks.

Although consensus was not always reached when the team coded quotations of text, more importantly there was complete agreement related to the broad themes that emerged throughout the coding process. All team members developed individual lists of themes, and the team met regularly to explore each theme to reach consensus on
inclusion in the findings. Throughout the process of theme identification, the team stayed cognizant of outliers within the data.

**Framework modification.** An important component of this dissertation is the development of a framework for implementing family driven care within a system of care. Chapter Two described the development of the initial framework based on current literature. Working from the initial framework, results from the QSA were examined in relation to the initial framework and significant modifications were made to reflect findings based on data from *Case Studies of System Implementation*. As noted in the Chapter Two, one of the purposes of this study was to develop an *empirically-based* framework for implementing family driven care. Because of the focus on an empirically-based framework, it was important that modifications to the framework be grounded in data from *Case Studies of System Implementation* and the focus groups conducted during the study—particularly in light of the lack of empirically-based frameworks in the current literature.

Entering into this process, the research team determined that there was a potential to find data that: a) support the framework components, b) provide additional framework components, c) support the overall concept of a framework component but require modifications to the framework component (e.g., discovering that advocating *for* families was less important than coaching families on how to advocate *for themselves*), or d) completely contradict a current component.

As discussed previously in this chapter, using a team-based approach to analysis was critical, providing multiple coders and allowing for consensus building across multiple team members as themes emerged from the data. The research team worked
together to identify the themes that were most salient to the framework for family driven care. This team-based approach was made possible with the inclusion of members of the original research team as well as a graduate student from USF’s Department of Anthropology, who assisted with the analysis.

Yin’s (2003) description of the iterative process notes that the process begins with an initial theoretical statement, in this case, the “statement” is a framework illustrating how families can be included as full partners within a system of care. Findings are then compared to that statement, revising the statement, and continuing the process as many times as is needed for the researcher to feel that it accurately reflects the data.

During framework modification, there were certain inclusion criteria that were important to the process. First, the team focused not only on points of convergence but also of divergence as data were examined in relation to the original model. Creswell (2003) stresses the importance of being mindful of presenting negative or discrepant information, and Patton notes that if one focuses on trying to prove that other factors are influencing the phenomenon being examined, it helps to guard against “stacking the deck” in favor of the original hypothesis (Patton, 1990, p. 462). The team stayed mindful of identifying differing or “rival” components for the framework.

The research team used the structures, processes, relationships, and values themes that were identified as characteristic of family driven care and compared them to components on the initial framework. During this process, the team determined whether or not a theme identified in the current findings was significant enough to justify inclusion in the framework. This was based on how strongly the theme emerged within the data—multiple occurrences of evidence and how powerfully respondents of varying
roles throughout the system spoke of a particular element as being critical to engagement of families at the system level. The team determined placement of each component by examining at what point the component was introduced as the system moved toward increased family involvement. For example, data indicate that having a family organization and at least one system leader working in partnership is a core initial condition for family driven care and is illustrated in the final framework as central to the process. The team also considered whether data from the QSA supported continued inclusion of components from the initial framework as well as whether they remained as stand-alone components or became part of another component. An example of this is the component Access to and Utilization of Information, which was a strong theme in the literature but appeared to be embedded within other components per QSA data. As such, it did not remain an individual component within the final framework. In addition, the team considered any possible changes to terminology, although no major changes were made. The important point is that the process consisted of using findings from the QSA to make team-based decisions about modifications to the framework. The second framework, which included all modifications based on the QSA, was used during the conduct of focus groups in Phase Two. The final framework, which includes modifications based on feedback from the focus groups, will be described in detail in Chapter Four.

Phase Two

Data collection.

Participants. Focus groups were conducted with individuals from system of care communities currently funded through the Children’s Mental Health Initiative (CMHI).
The focus groups were conducted to gather feedback on the second framework based on
their system of care experiences. Purposive sampling was used to identify participants for
the focus groups. Inclusion criteria were individuals attending the November 2010
National Federation of Families for Children’s Mental Health (FFCMH) Conference and
who:

- Were currently serving in the role of CMHI Lead Family Contact,
  Principal Investigator, or Project Director
- Were within a currently funded system of care community (through
  CMHI)
- Had knowledge of strategies for engaging families as full decision-making
  partners within their system of care, and
- Could link this knowledge to specific examples within their system of care

Study participants were identified with the assistance of the Technical Assistance
Partnership (TAP). Using their current distribution list, TAP emailed a recruitment flyer
(see Appendix D) to all currently funded CMHI system of care communities. Additional
recruitment also occurred during the FFCMH conference.

Separate focus groups were held with 1) Lead Family Contacts, and 2) Principal
Investigators and Project Directors. The focus group for Lead Family Contacts included 7
participants, whereas the focus group with Principal Investigators and Project Directors
included 5 participants.

**Procedures and instrumentation.** Krueger and Casey (2000) define focus groups
as “a carefully planned series of discussions designed to obtain perceptions on a defined
area of interest in a permissive, nonthreatening environment” (p.5). Focus groups are
conducted with a homogeneous group of individuals, are fairly small in size—ideally with six to eight participants—and have a moderator and assistant moderator (Krueger & Casey, 2000).

The Principal Investigator of the research project moderated each focus group and was supported by an assistant moderator. The assistant moderator aided with the audio recording, obtaining informed consents (see Appendix E), distributing stipends to participants, and note taking throughout the focus groups. Focus group questions probed for the following types of information related to the second framework:

- Framework components or terms that were unclear
- Based on participants’ experiences in system of care development
  - Components of the framework that belonged
  - Components that did not belong
  - Components that appeared to be missing
  - Components that needed to be moved elsewhere within the framework
- How participants thought this type of framework might be used within their system of care

Additional probes were asked for clarification purposes. The full focus group script is included in Appendix F. A stipend of a $20 gift card was provided to all participants at the end of each focus group.

**Data analysis.**

Transcriptions of each focus group were uploaded into ATLAS.ti and were coded for possible inclusion in the framework. Research team members individually coded the transcripts for each of the above components (i.e., “clarify,” “include,” “exclude,”
“move,”) and discussed each coded item. A similar team-based process was used for modifications to the framework as was used based on the QSA; however, the team made particular note of components that were mentioned during the focus group that were not part of the second framework. The team then discussed whether or not there were enough data to support its inclusion, reviewing the original dataset as well as re-examining the focus group transcripts. An example of this is Cultural Competence, which was identified as a component to be added to the framework. Further analysis and team discussion drew the following conclusion: although cultural competence was discussed quite a bit in the six sites, it was not linked to family driven care at the system level. For example, hiring bilingual staff to work with families ensures that at the individual treatment level families are driving care, but this issue did not present itself at the system level. However, the importance of the family organization being locally developed was specifically identified as important because it relates to the family organization being in touch with the needs of families in the community—whether related to ethnic, cultural, linguistic diversity or related to truly understanding the needs of rural or frontier or indigent families. Thus this concept is embedded within a description of the family organization. Modifications will be described in the final framework in Chapter Four.
Chapter Four:

Findings

Findings from this study are organized around the four questions that guide this research. They will be presented to include a finding statement, specific examples from the sites that participated in the study, and quotes as appropriate to emphasize the finding. Findings show that sites were not equal in terms of system level family involvement. Sites 2, 3, and 5 exhibited stronger family engagement at the system level than Sites 1, 4, and 6. This categorization of the sites based on level of involvement, although unintended by the research team, is noteworthy, and the reader will find that examples of identified structures, processes, and relationships rely heavily on Sites 2, 3, and 5. An example of board membership within the sites highlights these differences. In Sites 2 and 5, data indicate that family members are equal partners in all governance bodies and interagency committees. Families participate in all aspects of system planning and implementation. In Site 3, family members are active on many of the interagency committees across the regions. Data indicate that families are more active on committees facilitated by the Department of Mental Health, and committees facilitated by other system partners have included families more slowly. Inconsistencies in involvement persist, but agency partners have made significant progress in this area.

Site 4 offers a different picture. Data indicate that the Executive Director of the family organization serves on the governance board, but there is inconsistent inclusion
and participation (e.g., inconsistent involvement in strategic planning activities within the system). In Site 6, there is a position for a family member on the governing board, but the position remained vacant for a year. Data indicate that when another position on the board also became vacant, administers of the system began to prioritize filling these positions. The current stability of the Executive Director position within the family organization may also strengthen their resolve to fill this position, as respondents note that there had been several changes to the position in a short time. Finally, Site 1 did not have a position for a family member on the governing board. This individual was a member of cross-agency treatment planning teams at the individual child and family level and minimally participated in system level decision making. It should be noted that respondents from all six participating sites, regardless of their success in involving families in system level decision making, acknowledge that their work is never finished and they must continue their efforts to engage families.

The research questions that guided this study were the following:

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?

Data analysis for this set of findings began with a focus on the structures, processes and relationships characteristic of family-driven care. However, coding was expanded early during the data analysis process to also examine the values base of family-driven care that quickly emerged as a foundational component in communities where families were actively engaged in system level service planning and delivery decisions.

**Question 1: Structures, Processes, and Relationships Characteristic of System Level Family Involvement**

**Structures.** Structures are defined as the specified roles, responsibilities, and authorities that denote organizational boundaries and enable an organization to perform its functions. *A key finding related to structures is that having family involvement at the system level requires an engaged, locally developed, autonomous family organization that is regarded as an equal partner agency within the system.* Data indicate that such family organizations have a number of important characteristics, which include membership on governance bodies, local development, political and financial autonomy, equal partnership, and paid positions. These characteristics are described below.

**Membership on system of care governance bodies and interagency committees.** Family organization members have key decision-making roles on governing bodies and various interagency councils—sometimes as chairs or co-chairs of committees and teams. For example, in Site 2, the Executive Director of the family organization has an important role in the interagency administrator’s meeting, which includes directors of mental health...
and health and human services. In Site 5, the Executive Director of the family organization is a member of a county-wide cross-agency service system meeting that plans for services and supports for children with SED and their families throughout the county. Although directors are often committee members, other individuals from the family organization may also be members. For example, in Site 3, various members of the family organization are members of the leadership team at each of the community-based mental health centers throughout the state and also serve as co-chairs of community councils that provide a forum to share information about the system of care with stakeholders throughout the community—including outcome data and resources. The councils also offer an opportunity for families and other stakeholders throughout the community to express concerns or ask questions about mental health and educational services and supports.

Family organization membership is described as “not token,” and representation includes more than the same family member attending all interagency meetings. In fact, several respondents within these systems note that one person in a meeting cannot be the voice for all families within the community. As such, the systems may have multiple family members on councils and committees, or they may have multiple family representatives who attend different meetings.

**Local development.** Local development and a strong presence within the community are important characteristics of the family organization. Respondents note that although family organizations within their system of care often have associations with larger family organizations such as those at the state or national levels, it is important that family organizations are familiar with local conditions and the needs of
children and families within the community. In Site 3, although the family organization is a state-wide organization, there is local representation within the community-based mental health centers across all regions of the state. This allows family advocates to identify local needs and develop relationships with agency partners in the area. The impact of the local presence of a family organization is also observed in Site 5 where the family organization operates family resource centers that are located strategically throughout the county.

In Site 2, stakeholders describe a failed attempt to have a statewide family organization address the local needs of families in the region. After families in Site 2 expressed their discontent over having a family organization that did not know local families or understand the local needs of families in rural and frontier areas, a local family organization was created and is still an active part of the system of care. Further, respondents across all sites note that shared workspace or close proximity to other agency partners improve communication, strengthen relationships, and create more efficient and effective treatment planning for families.

**Political autonomy.** Data indicate that family organizations involved in system-level activities function independently of other agency partners and are not programs housed within a partner agency. Respondents in these systems note that family organizations must be politically independent from other agencies to ensure that the family organization’s priority continues to be support, advocacy, and training for families. Within Site 2, stakeholders indicate that because family organization staff are not under the direction of mental health staff, their activities are not dictated by traditional providers and differing perspectives may be voiced without fear of reprisal.
Data indicate that in systems with less developed family involvement, this independence is not present, with a stakeholder in Site 6 noting the organizational structure of the family organization within the mental health agency limits its political autonomy.

**Financial independence.** Although successfully established local family organizations may have used seed money and technical assistance from other system partners to get started, data indicate that they have become independent 501(c)(3) corporations. Such financial structures allow family organizations to earn independent revenue by contracting for the provision of a variety of services and to employ their own staff to carry out the activities of these contracts. Several of the family organizations have worked towards becoming members of a provider network (Site 6), have developed case rates for their work with families (Site 2), and have been able to bill for these services (sometimes this billing occurs through the mental health agency). In addition, system of care partners contract with the family organizations to conduct trainings, evaluation, and dissemination activities, all activities that are strongly evident in Sites 2, 3, and 5.

Data indicate that family organizations require technical assistance to build capacity in areas such as grant writing, training, and evaluation as well as the business skills necessary to manage a nonprofit organization. An administrator in Site 2 states,

*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.*

System stakeholders, including those within the family organization, note that developing such skills is critical for sustainability and emphasize that it is not in the best
interest of a family organization to simply “hand them money.” As one family resource center administrators within Site 5 notes,

*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.*

Respondents within the family organizations also note that as they engage in activities that help to sustain their organization (such as contracting for training, conducting evaluations, or writing grants), they must not be perceived as “too professionalized” by the families they serve, thus less like family advocates and more like traditional providers.

From the perspective of system leaders, data indicate that they feel a responsibility to strategize around sustainability of the family organization, particularly after CMHI funding ends. One administrator in Site 2 notes, “*Your responsibility is to make sure that they are successful, and that they grow into this organization. We’ve got to have this sustainability process for them. We need this organization.*”

**Partnership.** In systems that successfully engage families at the system level, family organizations are viewed as an equal partner to formal agency partners. Structurally, such partnerships are explicit, with roles and responsibilities of the family organization clearly defined and represented in organizational charts, collaborative agreements/memoranda of understanding, and strategic planning documents. All of these features are present in Sites 2, 3, and 5 with equal partnership clearly articulated in Site 2 as a “three-legged stool” in which the family organization, behavioral health, and child welfare are all viewed as critical partners within the system of care.
**Multiple paid positions.** Data indicate that family organizations involved at the system level typically have a number of paid family advocates in order for family support and advocacy activities to permeate the system. For instance, each region in Site 3 has several family advocates from the state family organization that work with families, engage in outreach activities, attend governance and council meetings as well as family team meetings, and conduct trainings; and in Site 5 the situation is similar, with family resource centers with multiple staff throughout the county addressing the needs of families and engaging in system level interagency collaboration, outreach, training, and evaluation. Within these systems, a focus is placed on capacity building—identifying family members to be hired as advocates, trainers, and evaluators, but also within the organization, teaching staff the skills needed to become leaders within the systems of care.

**Processes.** Processes are defined as the methods and procedures for carrying out organizational activities and often involving sequences or sets of interrelated activities that enable an organization to perform its functions. *A key finding related to processes is that having system level family involvement necessitates two distinct sets of processes: the first set is carried out by the broader system of care to support and facilitate family involvement. The other set includes processes initiated by the family organization in support of the system of care.* These two distinct types of processes and the components of each will be described below.

**Processes carried out by all system stakeholders to support family driven care.**

**Collaborative activities.** Within systems that successfully engage families at the system level, data indicate that there are many joint activities between family
organization members and other system partners. These activities often include joint
evaluation and quality assurance activities, strategic planning, joint decision-making
around funding, collaborative grant writing, co-presenting at state and national
conferences, and cross-agency problem-solving and conflict resolution. These appear to
be regular occurrences within Sites 2, 3, and 5, reflected in both interview data and
research team observations. Interview respondents in Sites 2 and 3 even describe
examples of joint state legislative advocacy efforts. Data from Site 3 indicate
collaboration particularly related to strategic planning, grant writing, and conference
presentations. It should also be noted that in Site 3, family members co-chair community
councils with an educational administrator. This reflects an important collaborative
activity that is quite unique to the site. All of the collaborative activities noted above
embody a frequently used expression in the family driven care movement: “Not about us
without us.”

Training and coaching. Data indicate that training activities are provided
specifically for agency partners, families, and jointly. Interview respondents from Sites 2,
3, and 5 describe trainings on traditional system of care and wraparound topics for
providers, but they also conduct trainings related to family driven care and working with
families in a strengths-based way. Perhaps more importantly, the data provide multiple
examples of the use of coaching and modeling to bring training into everyday practice.
Coaching and modeling focuses on the specifics of how to involve families. For example,
family members provide coaching and/or model how other families can be involved in
decision making and how one can identify and build upon strengths within a particularly
challenging family. It should also be noted that family organizations in participating sites
often engage in cross-system training—sometimes as participants, but also as trainers or as co-presenters as a way to share their experiences. In systems that successfully involve families at the system level, stakeholders describe the powerful impact of family participation and note that hearing stories directly from families about their struggles is actually more powerful than traditional training.

Interview respondents also describe trainings that are specifically targeted towards families. In addition to system of care, wraparound, and parenting trainings, these systems provide trainings on topics such as leadership development and conducting evaluations. Although these trainings may be conducted by any system partner, trainings in these sites (Sites 2, 3, and 5) are often hosted or conducted by the family organization. Stakeholders in Site 5 note that the family organization is contracted with to provide many different types of trainings throughout their system. A case manager in the site, describing the training role of the family organization notes,

...apparently they just encouraged their staff to participate in System of Care trainings. To become essential trainers. To move from being, you know, on one side of the desk to the other. Which demonstrates their competency. To be part of the training team.

Respondents in Site 3 describe their statewide family conference, which is attended by staff from across the system but particularly by staff from mental health.

*Family attendance and active participation in governance and committee meetings.* This process is reflective of the concept of membership described in the Structures section, but extends this concept into action. For example, in Sites 2, 3 and 5, members of the family organization not only have a seat at the table but very actively participate in governance meetings. Family participants describe their experiences of speaking up in meetings and system partners listening to their ideas, discussing them, and
incorporating those ideas. This involvement also includes points at which the family representative may disagree with the rest of the governing body. In Site 2, the Executive Director of the family organization notes that when she disagrees, all members stop and work to resolve the issue, which she describes as different than prior experiences in other systems. As one family member in Site 3 describes attempts at improving collaboration with the Department of Education, she notes a shift that has occurred:

They actually come up to you and will ask what you think about something. Or, did you attend something and what did you think about what was said, or what they’re planning to do. And, that’s a big difference from...In the beginning, it was just you sit there...I was a presence. Now, I’m a player.

Evaluation activities and dissemination of findings. Within systems that successfully engage families at the system level, data show that the family organization is an integral part of the evaluation team. Not only do they serve as data collectors, connecting with families within the program to gather needed information, but they help to analyze and disseminate findings. These activities are strongly evident in Sites 2 and 3, with a member of the family organization in Site 2 articulating their important role noting,

We get involved at every level [of the evaluation] which is really cool. I don’t think anything gets done in that office, as far as any sort of big meetings without contacting us and making sure that families get involved. It’s just an automatic...

Stakeholders within this site also describe the family organization’s insistence that members become paid as evaluators, a role that they currently hold within the system. There is a notable difference in evaluation activities within sites that have family involvement at the system level. All sites within the study describe how they collect and utilize evaluation data related to family engagement at the individual child and family
treatment planning level. However, sites with family involvement at the system level have shifted from families as objects of the evaluation to active, trained evaluators.

**Processes carried out by the family organization to support the system of care.**

*Capacity building of families.* In systems with family involvement at the system level, the family organization engages in a variety of capacity-building activities with families. As mentioned above, training of families is an important process that includes not only training families to develop skills around parenting and advocacy, but also to develop skills as evaluators and leaders within the system. In addition to training activities, members of the family organizations mentor and coach families to participate at all levels of the system and to advocate for themselves in an informed and constructive way. It is important to note that within Sites 2, 3, and 5, members of each family organization clearly articulate their role as not one that advocates for families but rather one that helps families develop the skills to advocate for themselves. As a member of the family organization in Site 3 describes,

*We support the families. We do not speak on behalf of the parents. So, that’s one thing that we stress in our parent organization. We are the support. We can attend the IEP meeting. However, we do not speak that, ‘Hey, this is the law.’ Never. We are supporting because it’s very hard when you’re in an IEP with 6 professionals and just Mom. And, sometimes Mom does not understand.*

In Site 5, a member of the family organization describes the process of goal setting and rehearsing with parents to prepare for a school meeting after a parent’s outburst at his/her child’s school. This type of coaching was present within all of the sites with family involvement at the system level. It should be noted that coaching occurs in many family organizations and by lead family advocates within systems of care on a regular basis. However, the family organizations discussed above have multiple staff
members who continually engage in these activities, thus impacting more families and agency partners.

Within systems that successfully engage families at the system level, stakeholders also describe the process of identifying families to grow into trainers and leaders within the system. Leaders within the family organizations describe this as a critical step for sustainability of the organization but also acknowledge that not all families are interested in taking on these roles.

*Strategic outreach to system partners.* In systems with family involvement at the system level, family organizations engage in a great deal of outreach to system partners. Although this is an important precursor to relationship building (to be discussed below), strategic outreach should also be considered as an important process and deliberate action conducted by members of the family organization. For example, members of the family organization in Site 5 describe regular calls to partner agencies for the purpose of problem-solving, planning, strategizing, and sharing information with other system partners, in the same way an employee of any other partner agency would. Interview respondents describe the importance of reaching out and making personal connections—calling individuals from partner agencies, acknowledging the challenges they face in working with a particular family, encouraging the individual to engage the family in the decision-making process, and thanking them for the work they are doing with the family. Family members describe this cross-agency outreach as critical to moving a system toward one that is more family-driven.

**Relationships.** Relationships are defined as trust-based links creating connectedness across people and organizations. *The key finding related to relationships*
is that the process of relationship building is a critical characteristic of family involvement at the system level. Findings related to relationships suggest that the process of relationship building is more critical to developing system level family involvement than having a specific list of relationships that should be developed. It should be noted that relationships between particular agency partners are also important, particularly those observed between members of the family organization and other system partners; however, the core components of this finding relate to the relationship building process. Relationship building includes the following components described below.

**Modeling of strengths-based interactions with families and across agency partners.** Data indicate that strengths-based interactions are in stark contrast to the adversarial relationships that were previously observed between providers and family members, and that these reflect a team-based problem solving process that is far more inclusive of families. For example, in Site 2, one respondent describes a provider’s resistance to the wraparound process and notes that this should not be viewed negatively but rather as an opportunity to show them how this team-based approach, which has a strong family involvement component, makes their jobs easier.

An important finding related to strengths-based interactions is that members of the family organizations accept an enormous amount of responsibility for developing positive relationships with agencies. Members of the family organization describe strengths-based interactions with families and with traditional providers as parallel processes. An example of this strengths-based approach is illustrated in relationship building between a supervisor within the family organization and a probation officer in Site 5, who notes,
So when I call up the Probation Officer I’m just as strength-based with them as I would be with the person that I’m talking to them about. I’m always interested in, you know, their life...If somebody sounds tired, I make a point of saying, “You must have had a rough week.” I mean, just so we can create the kind of relationship that we want. And I always say, “Please feel free to call on us at any time. And, you know, we’re certainly gonna call on you. Thank you for what you do.” You know, just building a relationship. ‘Cause you have to. You know, you have to. And it really works better for everybody ’cause the goal has to be, “What can I get to help my clients?” And I’m not getting anything if I’m making enemies.

Conversely, adversarial interactions between members of the family organization and traditional providers are recognized as creating barriers to cross-agency collaborative activities such as problem-solving and service planning at all levels of the system. A respondent within the family organization in Site 2 describes an evolution of the family organization from one that was adversarial:

*In the beginning they think we thought we had to go in there like gang busters. By gosh, we’re going to do it our way. We had to learn, too, they’re not the enemy. They’re really people that we really need to work with. Some of our families have been through the systems and not always had the best experience. But you get more flies with sugar than you do with vinegar. We’ve learned to have to do that. We teach our families to do that too.*

**Long-term investment.** In systems that successfully engage families at the system level, interview participants at all levels describe relationship building as a strategic, one-on-one process that is continuous and must be repeated regularly because of the turnover in agency staff and the receipt of new families into the system. Respondents note, however, that they constantly work to develop these new relationships because they are so important for long-term involvement of families in the system. In Site 3, a family member describes this slow process:
I’m not saying it happens on a huge scale. It’s happening at a one-to-one level. But, that’s okay. Because, you know what? Tomorrow it’ll kick up a notch. And, in another 6 years, maybe another notch. It’s not gonna happen overnight, unfortunately. I probably will never live to see the day. But, that’s okay.

Conversely, interview respondents also describe the long-term investment and issue of turnover positively, noting many attempts to “re-educate, re-educate, re-educate” system partners unsuccessfully. They note that sometimes there is nothing to do but patiently wait for them to leave. As one respondent in Site 3 notes, “You get some dinosaurs out there, that just…they’ve got to retire.”

The engagement of families within child welfare or juvenile justice may be perceived as opposing agency mandates to protect children or the community. In Sites 2 and 5, respondents describe struggles in working with child welfare, juvenile justice, and county attorneys. In particular, respondents from Site 5 note juvenile justice’s focus on community safety and the risk they take in implementing wraparound services with the youth back in the home. As a result, members of the family organization work with families and agency partners to find ways to include families. One respondent provides an example of her liaison work between families and child welfare in which she notes that she works with family members so they understand that being more cooperative with child welfare is in their best interest (coaching them in positive interactions) while working with child welfare to be more open to having families engaged in the planning process. Although this example is at the individual treatment level, it reflects systemic collaborative activities across agencies.

Interview respondents describe an acknowledgement that agency partners have varying degrees of buy-in in regards to the involvement of families in system level
decision making. Data indicate that a great deal of effort, particularly on the part of family organizations, is made to work with agency partners to encourage them to open themselves to a collaborative, team-based process with families and to model these actions. As one member of the family organization notes,

So I’m not gonna say, like, ‘I can’t believe you said that to that family.’ I’m not gonna say that. I’m gonna say, ‘You know, it seems to me like what we need to look at is the strengths of the family.’ I’ll just keep bringing them back. And bringing them back.

In addition, respondents across sites with system level family involvement discuss the importance of assessing how families can participate in a meaningful way within the system. They note that families are at various stages of meeting the mental health needs of their children and may only be able to focus on their family at the time. Other family members have the potential to become strong trainers, mentors, coaches, and leaders within the system but need to build capacity to reach their potential. Still others are ready and willing to become engaged in system level service planning and delivery. Stakeholders note that it is important to recognize the strengths and limitations of families and allow the opportunity for families to participate as much as possible given their involvement in caring for the needs of their own children. This is a purposeful activity that is viewed within these sites as important to the long-term success of family driven care.

**Relationship building develops trust.** When family driven care is reinforced at all levels of the system through relationship building, trust develops across all partners within the system. Trust is strongly reflected in collaborative activities around treatment planning across agencies but is also very evident in system level planning and decision making. Data indicate conscious attempts are made to understand varying points of view
because all partners want to do what is best for the child and family. For example, in Site 2, members of the family organization describe working with families so they will understand that the agencies “aren’t the enemy” and are trying to help while also pointing out that agencies may have slightly different priorities that they are responding to. Respondents also describe risk taking that occurs as trust is developed. Stakeholders in Site 5 provide examples leaders relinquishing power by having families and youth attend and actively participate in governance meetings:

I think it was the willingness to take a risk and have the youth come together and say, “Tell us what helps and what harms, and guide us.” That was such a huge shift. And such a huge risk to take, I think. And it was because of a leadership that was willing to take that risk.

Participants also note that this risk taking is also evident in agency partners—particularly as trust is developed between the family organization and traditional agency partners—with both parties truly believing that recommendations being made are in the best interest of the child, family, and community. This point supports the previous finding related to strengths-based interactions of the family organization. Members of the family organization realize they are asking agency partners to take a risk by inviting families to the table in agencies where this is not required; however, the relationships they have built provide an avenue for this to occur.

Trust is also reflected during the problem-solving process. Family members articulate an ability to express dissenting opinions without fear of reprisal because of the trust that has developed across partners. A family member from Site 2 clearly illustrates this point: “Because the safety of the whole system is built on people that can question each other...You’ve gotta have a relationship, but you’ve gotta be able to feel safe...”
This point is further emphasized by a service provider who notes as families have gained their voices, providers are willing to be uncomfortable with what the families say and to work through issues: “Cause I’m a firm believer that...you’re not always gonna be a united front. It’s just not gonna happen. There has to be the value early on to embrace confrontation.”

The following quote from a service manager in Site 5 summarizes this broad finding well: “Relationships are key. I think the relationships with family, with individual workers, are just key. They’re just key. I can’t say that enough."

**Values.** Values are defined as an ideal accepted by an individual or group. A key finding related to values is the presence of a shared value for involving families in system level service planning and decision making. Data indicate that stakeholders in systems that successfully engage families at the system level embrace family driven care because they view it as the right thing to do. They recognize that families are “the experts” and can contribute meaningfully in service planning and implementation, and they acknowledge that family involvement improves services and supports within the system. The Executive Director of the family organization in Site 2 clearly articulates this level of respect, noting,

*When I go to the state Federation meetings with other family groups from the rest of the state, I really realize the... how well I am treated here compared to how well they are treated and how well my organization is treated and respected and I use this term maybe not in the sense you think of, we are honored. When we are invited to a meeting, it is not a token invitation. When we are asked our opinion, it is not just so they can say we asked the family group. When I disagree with something, they don’t just move on. I was shocked when I took this position...They truly believe what they say.*
System leaders actively work to infuse these values into the system. The work of actively infusing values into the system is accomplished by articulating the expectation that families will be involved in decision making, modeling engagement of families in system level planning and delivery, and promoting family driven care with system partners. A mental health administrator may initially lead this effort, which would be expected since systems of care (and the associated value of family driven care) are viewed as a mental health initiative, but other system leaders (in addition to the leader of the family organization) begin to share this value and articulate its importance within the system. Stakeholders at all levels and within several sites (particularly sites 2, 3, and 5) describe leaders who genuinely value family participation. A service manager from Site 5 notes, “The fact that there’s leadership that values families and families’ voices. And sort of the community team-building focus that includes families and kids and providers. Relative to other systems, I think it’s very much a strength.” This value reflects a true respect for families in decision making and partnership in the team-based planning process. In Site 3, members of the family organization note how meaningful it is to have the mental health director actively participate in the family organization’s statewide annual conference. In Site 2, an interview respondent describes promoting the value of family driven care into system partners and holding each other accountable when they would leave families out:

*I remember we thought, one thing around the grantee meetings, they require you to take all these people with you. Well, that’s very strategic. We would take Health and Human Services folks, child welfare, juvenile justice, and education. We’d haul them off to these conferences. It’s kind of like you go somewhere else and you hear the same thing. And they began to hear families talk. And I can remember [HHS supervisor] saying the first time we exposed her to that. It was like this transformation. It just became very*
important. And we had this kind of relationship when I’d forget about the family voice, somebody else would hold me accountable all the way around. If [HHS director] would forget about the family voice, I’d be like, “wait a minute.” So we had this ability to hold each other accountable to these principles and values, and we just made a huge commitment to the family organization.

Interview respondents note that not all agencies are fully invested in family driven care and identify particular agencies as needing reinforcement of this value. For example, in Site 3, a member of the family organization describes working closely with probation to reinforce this value through relationship building; in Site 5, members of the family organization focus on reinforcing this value with child welfare. This targeted work was also observed at the individual treatment level, as the lead family advocate in Site 1 describes working with treatment team members to shift their thinking about families.

**The family organization is valued as an equal agency partner within the system.**

The critical role of the family organization in system level family involvement was described in findings related to Structures. However, underlying this structure is a genuine belief that the family organization *is* and *should be* an equal partner within the system. This is particularly evident in Sites 2 and 5, when members of the family organization and traditional system partners (particularly leaders) describe collaborating on joint training, grant writing, and evaluation activities as well as working together on system planning and problem solving. These data are strongly supported by onsite observations of interagency governance and planning meetings in which all system partners work together as equals. One respondent describes it as a “continued equal partner attitude.”

**System partners engage in self-reflection.** A necessary component of infusing a shared value is that system partners engage in continuous self-reflection and open
themselves to different models of decision making. Data indicate that a continuous
process of self-reflection is necessary to ensure system level family inclusion. A family
member in Site 3 notes the willingness of system leaders to look at themselves critically.
In Site 5, a site with particularly successful family involvement at all levels, a manager
describes this self-reflection:

*I think that’s the other things we have learned. That we have to
believe it, speak it, and do it. And sometimes I think we believe it
and we think we’re doing it, we can certainly speak it, but are we
really doing it? And it’s hard.*

**The Mandate of Family Driven Care**

Questions Two and Three of this research are specific to implementation of the
federal mandate of family driven care as described in the Cooperative Agreement for the
Children’s Mental Health Initiative (CMHI). The Request for Applications (RFA) notes
that one of the goals of the CMHI is to “implement full participation of families and
youth in service planning, in the development, evaluation and sustainability of local
services and supports and in overall system transformation activities” (CMHS, 2010, p.
6), and applicants are required to provide a description of how families and youth are
involved in the governance and oversight of grant activities. Before discussing findings
related to these two questions, it is important to gain clarity around the specific
expectations of the systems of care participating in the cooperative agreement. A couple
of important points should be made before proceeding. First, as described in the literature
review, it was not until 2005 that the term “family driven care” was introduced and
defined with the RFA, and the role of families within the grant program was expanded,
with families sharing in decision making and responsibility for outcomes. In the overall
history of children’s mental health, family driven care is considered a rather new
development. Secondly, each of the systems of care that participated in this study
developed their systems long before family driven care was mandated or even regularly
considered in a system of care. However, data reflect that some of these sites viewed the
participation of families and the family organization as critical to system development
and implementation.

The CMHI Cooperative Agreement requirements. The current cooperative
agreement provides very specific requirements related to family driven care for
communities funded through the initiative. A core component includes the hiring of a
full-time Lead Family Contact. This position is usually filled by a parent or other family
member of a child and with SED who has received or is currently receiving services in
the system. This individual has “full inclusion” on the governance body, and his/her
many responsibilities include:

- Provide support services for families within the system
- Work in partnership to develop, implement, and evaluate the system of
care
- Create or work with the existing family-run organization

The funded community also has several responsibilities, which include:

- 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. The RFA
emphasizes that the family run organization should receive resources to support and sustain the infrastructure that is essential to ensure an independent family voice

- 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)

Although the mandate addresses family involvement at the individual treatment level as well, the activities described above focus on improving family involvement at the system level, which is the focus of this dissertation. As such, findings related to Questions Two and Three will discuss facilitators and impediments to *system level* family involvement specific to this mandate as identified in all six sites from the original study.

It is important to note that facilitators and impediments to the mandate of family driven care go beyond whether the structures and processes as reflected within the RFA are being actualized, but in fact lead again to the concept that a shared value of family driven care across system partners is the foundation for systems that have included families at all levels of decision making. However, the structures and processes emphasized in the RFA serve as indicators that a system is working towards family driven care.

**Question 2: Factors that facilitate implementation of the policy mandate of family driven care.** The mandate requires that funded communities describe how administrators and staff share power, resources, authority, and control. *A key finding*
related to factors that facilitate implementation of the policy mandate of family driven care is the presence of an equal partnership between the family organization and other system partners. In systems that have family involvement at the system level, the family organizations have authority equivalent to those of other system partners. This critical component allows all other requirements to fall into place. It is important to note that the RFA requires administrators within the SOC to share power and authority with families. It does not require equal partnership, and sharing power does not always translate to equal partnership. Findings below are well supported by findings discussed in Structures and Processes previously described; therefore, specific examples with quotes are kept to a minimum.

**Lead Family Contact position and family involvement in planning, implementing, and evaluating the system.** Although the title of the position may vary and the authority levels of the individuals differ, all sites who participated in this study have an individual who serves in the capacity of Lead Family Contact. In communities with family involvement at the system level, the Executive Directors of the family organizations fill this role. In systems with strong family involvement, these individuals are a core member of the governance team and are actively involved in planning, implementing, and evaluating the system of care. Five of the six sites have a position for a Lead Family Contact on the governance board, but this does not always translate into true shared power, with some positions appearing token or even unfilled. The activities of the Lead Family Contact within sites with family involvement align closely with mandate requirements—they are members of the family organization, and both they and their staff provide support, training, coaching, and mentoring for families within the system. Not
only the Executive Director but also family organization staff are involved in a variety of activities related to planning, implementing, and evaluating the system.

**Sharing of power and authority.** Data indicate that in sites with family involvement at the system level, leaders within the system share power and authority with family members. In system planning and implementation, this includes not only governance board membership, but also involvement in strategic plan development and implementation (strongly present in Site 3), as part of the evaluation team (noteworthy in Site 2), involvement in hiring decisions (as noted in Sites 2 and 5), and funding decisions (particularly noteworthy in Site 5).

**Incentives for families.** The mandate specifies that the system of care must provide incentives for families who participate in system development. In systems with family involvement at the system level, family members who participate in system planning are employees of the family organization. As a result, incentives appear to not be an issue. Data indicate that this is not the case across all sites, with some interview respondents noting lack of incentives as a barrier to family involvement. This will be described in further detail within the Impediments discussion.

**Provision of financial support for the family organization.** This requirement of funded communities is particularly noteworthy, as data from this study indicate that support of the family organization appears critical as it relates to seed money to support the family organization but especially other resources such as training to become evaluators and trainers within the system; assisting members of the family organization to develop leadership and business management skills; and providing support in other ways to ensure sustainability of the family organization, such as grant writing and contracting
for services. The RFA emphasizes the importance of the family organization receiving resources to support and sustain an infrastructure to ensure an independent family voice but does not provide specifics related to these resources. As such, it could include any or all that are mentioned above. As indicated in findings related to Structures, at some point in development the family organization transitions to one of greater financial autonomy, and interview respondents within these systems emphasize the importance of this autonomy.

**Involvement of a CMHS-funded Statewide Family Network grantee.** The mandate for family driven care notes that funded communities should work with Statewide Family Network grantees if any are present within their state. Data were not collected related to potential collaborations between these two grantees and as such cannot be addressed.

**Question 3: Factors that impede implementation of the policy mandate of family driven care.** A key finding related to factors that impede implementation of the policy mandate of family driven care is the lack of shared power and authority with families or the family organization. As with factors that facilitate the implementation of the mandate, the willingness to share power and authority with families appears ultimately driven by a shared value within the system that families should be involved in planning, implementing, and evaluating the system of care. The factors below, however, focus on the structures and processes as clearly delineated in the RFA.

**Lead Family Contact position and family involvement in planning, implementing, and evaluating the system.** All sites examined during this study have an individual who meets basic criteria for the position of Lead Family Contact within their
system. However, these individuals have vastly different roles, responsibilities, and authorities. All have a primary role of supporting families within the system of care, but beyond this characteristic, there is great variability.

**Shared governance.** Data from Site 3 reflect inclusion of families on many committees and shared decision making; however, several members of the family organization note that collaborations are strongest with the Department of Mental Health and inclusion on committees with other system partners is sometimes token. The Executive Director of the family organization in Site 4 participates in some interagency committees, but this participation is inconsistent, and minutes from a strategic planning retreat reflect no family representation during this important planning process.

Interview respondents in Site 6 note that there is a place for the Executive Director of the family organization on the governing body, but due to significant turnover in Executive Directors, the board position was vacant (and remained vacant even though the role of Executive Director had been stable for 6 months). Interview respondents note that they anticipate the position to be filled soon, primarily because there are other vacancies on the board that need to be filled. Site 1 had no family representation on their governing body. Policy decisions were made by administrators of each lead agency and a local judge.

**Family voice.** Representation on boards and interagency committees is not taken lightly. Interview respondents holding these positions note that they cannot represent all voices of family members in the system. One respondent from Site 1 notes,  

*I am not the voice of the parents. Because my concern might not be Mary Jane’s out there. You know what I’m saying? ...So, sometimes I really don’t like the word... that, “Oh, I am the voice of the parent.” No, we’re not. We’re out there to support the*
In addition, data reflect that stakeholders at all levels of the system note that identifying families to represent family voice in system level decision making is very difficult when the families themselves are in crisis. As a respondent in Site 5 notes,

*One of the things I’ve often wondered about family involvement is when a family’s got their kid actively in need and in crisis sometimes because you can see family involvement at the kid level, there’s different kind of family involvement at this organizations level at the system level. When families are stressed, I wonder how they make a transition from, you know, through concern for their own kid, to the kind of system level concern that you’ve got because you’re working at an important but very different level than when you were concerned about your son.*

*Adversarial interactions.* Interview respondents from family organizations describe unsuccessful collaborations when the family organization is adversarial with other system partners. Respondents in Sites 2, 3, and 5 all describe an important transition within the family organization, and a respondent from Site 2 clearly articulates this change:

*[The family organization] evolved from learning that you just don’t jump up and down and demand to teaching the family to make sure they express their needs and express it in a way that is socially acceptable to help families through crisis without necessarily being a person that identifies what lane you’re going down. They have to be careful that they listen to the family and hear the family voice and make sure other people listen to that family voice.*

*Sharing of power and authority.* An impediment to implementing the mandate for family driven care is the reluctance of administrators to share power with family members. This clearly impacts the family member or family organization’s ability to
collaborate with system partners in planning, implementing, and evaluating the system.

An interviewee from Site 1 notes,

> And I think this is how it’s been. Historically, is that you have leadership in the front, and family voice is an afterthought. So the leaders, kind of in their grandiose thinking, are “We are the leaders, we know everything, we’re going to do it this way.” That hierarchy of power. And they put themselves first, with a great idea, but they aren’t delegating their power and authority often, is what I’m seeing.

Even within systems with active family involvement at the system level, respondents describe inconsistencies across agency partners and within agencies in collaborating with families and the family organization. Data indicate that these inconsistencies occur for a variety of reasons, including traditional provider-family hierarchies and lack of respect of families as collaborators as well as agency mandates that may exclude parents. Respondents in Site 5 describe the challenges in working with an agency, such as child welfare, where parents may have limited custodial rights. They describe making efforts to convince these agency partners that inclusion of families in decision making (whether at the individual treatment or system level) improves services and supports within the system. These respondents acknowledge that there are safety concerns that agencies such as child welfare must consider at all times. A respondent in Site 3 describes individuals from education citing confidentiality as justification for not sharing information with the family organization in order to assist families.

Finally, partnership in decision making is also challenged by the notion that system development must occur before families become involved—the idea that a system must have a table before families or a family organization can be invited to join. A respondent in Site 1 notes: “The last thing you need to do is to bring families on board
without identifying the scope of the effort.” In this example, families are not viewed as contributing partners in the system development process, which, within the RFA is an important Year 1 activity.

**Incentives for families.** As described earlier, in systems with multiple paid staff members within the family organization, incentives for families participating in system level planning, implementation, and evaluation are not a significant issue. Data indicate that even in systems with a less active family organization, system stakeholders report paying families to participate, although some of them, such as Site 1, describe an evolution to a paid family position and do not indicate whether the individual was paid for prior participation. Another respondent notes that it is a significant issue when everyone at a meeting is paid except for the family representative. Respondents also describe issues related to transportation and child care create barriers to participation at both the individual treatment and system levels.

**Provision of financial support for the family organization.** The RFA for the CMHI cooperative agreement requires that funded communities provide financial support to sustain the family organization. Respondents within the six sites provide varying perspectives on how best to support the family organization. Previously in this chapter, findings were discussed related to support of family organizations. These types of supports included seed money to get the family organization operational but then a shift towards financial independence by building capacity to engage in activities such as evaluation, training, billing for services, and grant writing. These family organizations then became 501(c)(3) organizations. However data indicate that sites without significant family involvement have structures in place that are not conducive to the development of
a truly independent family organization. In Site 6, an administrator describes frustration at not being able to get financial support for a family organization, which prompted the system’s application for federal funding through CMHI. The family organization, however, remains under the umbrella of a program within mental health. Another respondent within the system notes that the family organization is not autonomous and that the program has not done what is necessary to foster autonomy for the family group. In Site 1, a family member who holds the sole paid family advocate position within the system even more strongly articulates her challenge in attempting to begin a local, independent family organization:

> And for them to be pretty opposed to [implementing an independent family-run organization] I thought was, I don’t know...Again, the hierarchy of power, that control, they wanted to have some kind of control over it. I think they’re afraid to let go.

**Involvement of a CMHS-funded Statewide Family Network grantee.** Data were not collected related to any potential collaborations between these two grantees and as such cannot be addressed.

It should be noted that there are often additional factors external to the system of care that may facilitate or impede family driven care, such as particularly strong support of policy makers and funders at the state or local level who may contribute additional funding to jumpstart the initiative or even withhold funding when families are, for instance, excluded from the governing board (as reported in Sites 2 and 6 respectively). Sites, however, generally have minimal control over external factors. This discussion has focused on factors within the control of system of care stakeholders, as they are ultimately responsible for carrying out the policy mandate.
Within all six participating sites, respondents noted that more work needs to be done to engage families. This includes not only at the system level but even at the individual treatment level. Data clearly indicate that family involvement at the individual treatment level has been more successful than at the system level across all sites, but challenges exist and all sites acknowledge issues related to providers who still function within a traditional provider-family paradigm, agency mandates that may exclude parents (particularly within child welfare and juvenile justice), negative past experiences for the family, existing stigma, and language barriers.

**Question 4: Empirically-Based Frameworks**

Question Four of this research study describes three frameworks that illustrate implementation of family driven care. The first, a theoretical framework based on extant literature, was developed early in the research project and was presented on Page 68 of this dissertation. A second framework, based on a secondary analysis of data from *Case Studies of System Implementation*, will be very briefly described during this discussion. A final framework, evolved from the second framework to incorporate feedback from focus groups conducted with Lead Family Contacts, Project Directors, and Principal Investigators from currently funded CMHI system of care communities will be illustrated and described in detail. Figure 9 depicts the iterative process used to arrive at the final framework that illustrates implementation of family driven care.

![Figure 9. Three-Stage Process of Family Driven Care Framework Development.](image-url)
**Framework 1: Derived from extant literature.** Figure 8 on Page 68 illustrates the initial framework for implementing family driven care, proposed at the beginning of the study. As a brief review, the framework was derived from empirically based literature and focused on core components that the literature suggests are critical to successfully implementing family driven/consumer driven care. The framework depicts components of system context, assessment of progress toward family driven care, strategies, and an outcome of family driven care, the structure of the framework loosely based on a logic model format. The context provides a background and foundation for activities that occur within the system. The outcomes system stakeholders seek should ultimately guide activities within the system; however, assessment of progress toward family driven care guides the strategies that are implemented and should be an ongoing process, which is reflected by an assessment loop.

**Limitations of Framework 1.** There were a few noteworthy challenges with Framework 1. First, there is a dearth of literature in children’s mental health that addresses empirical frameworks related to increasing family involvement in organizational and system level planning and delivery decisions, and although there is more literature related to expanding the role of families in individual treatment decisions, these components do not translate particularly well to broader decision making. As a result, it was necessary to examine consumer and stakeholder involvement in organizational and system level decision making beyond the field of children’s mental health in order to develop the framework. As such, some components identified within the initial framework were not supported by data from the QSA.
Secondly, the framework provides information on components—the “whats” of stakeholder inclusion, i.e., the things that a system might have in place, such as training or membership on governing boards—but provides limited information on incorporating strategies—the “hows” of this concept, i.e., the activities that systems engage in to infuse a value of family driven care or how relationships are developed across the system. Finally, the initial framework, in a far too linear manner, attempts to describe a concept that is extremely complex. *A key finding related to empirically-based frameworks is the need to incorporate strategies and activities that have been used to develop successful family driven care rather than a more limited focus on the appropriate components of family driven care.*

**Framework 2: Derived from secondary analysis.** The secondary analysis conducted during this research project provided much-needed information for capturing the complexity of implementing family driven care and filling many of the gaps in the framework due to a deficient literature base. The second framework, illustrated in Figure 10 attempted to capture ongoing efforts to infuse the value of family driven care into systems with family involvement at the system level.
Figure 10. Framework 2: Expanding the Orbit of System Level Family Driven Care
In addition to reflecting a more fluid process, the reader will note emphasis on particular components that are more prominent in the implementation of family driven care. Most notable, the critical role of the family organization and its partnership with the system partners emerged as core to this process. These entities work together to infuse the value of family driven care into the system, developing strengths-based relationships and engaging in activities such as training, coaching and mentoring families as well as training agency staff and modeling strengths-based interactions with families. It also became apparent that the shared vision of family driven care across system partners may not be shared early on in the implementation of family driven care. Data indicate that when systems begin to work towards engaging families at the system level, there may be only one leader within the system, aside from the Executive Director of the family organization, who is committed to this process. This leads to the next significant change to the framework, which was the removal of the notion of a culture of inclusion. Data indicate that the significant shifts in organizational culture that occurred developed over a significant period of time and become an outcome of the process. In fact, respondents describe a long-term investment of working one-on-one with agency partners to shift their thinking about the role of families.

Although formal assessments are conducted to examine family driven care at the individual treatment level, assessment of system level family driven care is a much more informal process of self-reflection. As such, assessment was removed from the framework. Strategies identified in the literature were supported by data from the QSA, which highlights two points: 1) identification of some of the components necessary for family driven care are being captured in the current literature base, and 2) these
components, although often described as strategies are actually more concrete components than actions. For example, advocacy, mentoring and support are generally considered important activities. However, in sites with system level family driven care, respondents are able to describe very purposeful action related to these activities. They describe advocacy as teaching families how to advocate for themselves and strongly emphasize role playing and modeling of interactions with agency partners so families can advocate for themselves successfully. These types of activities are often not captured, i.e., the “hows” of this process. Access to and Utilization of Data, described in the first framework was found to be more embedded within partnership, communication, and even within the process of self-reflection but was not emphasized strongly enough to warrant a discrete component.

The reader will also note an attempt to reflect the developmental progression of family driven care over time. Data reflect stages that occur within communities who engage families in system level decision making. These stages are described at the bottom of Figure 10 but were incorporated into a single graphic for the final framework, and will be explained in detail during the discussion of the final framework.

**Modifications to Framework 2.** Focus group participants provided feedback on the second framework. Recommended changes suggested by the focus groups were fairly minimal and related primarily to the location of particular components within the framework. For example, there were graphic components that were confusing to participants, such as the placement of some of the lines and arrows. In addition, participants offered suggestions on the location of the family organization and system of care leaders within the model, and they noted that the attempt to illustrate the
developmental progression of family driven care within the system was not clearly communicated. Regarding content, most respondents agreed with the content but made suggestions to illustrate that these activities are ongoing—not occurring only once during the implementation of family driven care. Finally, respondents in both focus groups mentioned the lack of cultural competence reflected within the framework. The research team revisited data from the six sites, and although it was discussed, it was only tangentially related to family involvement at the system level. It was often mentioned related to individual treatment, for instance, ensuring that SOC communities have bilingual clinical staff. However, this was a priority in all systems regardless of whether or not they were attempting to engage families in system level decision making and was not specific to communities who were successfully engaging families. It should be noted that the description of the family organization includes local development and the importance of addressing local families’ needs. Data indicate that in communities with family involvement at the system level, family organizations are sensitive to the racial, ethnic, cultural, and linguistic diversity of their families.

**Framework 3: Final framework—Expanding the Orbit of System Level Family Driven Care.** The framework *Expanding the Orbit of System Level Family Driven Care*, illustrated in Figure 11, depicts the development of system level family driven care based on all information collected throughout the course of the research project.
Figure 11. Final Framework: Expanding the Orbit of System Level Family Driven Care
If the reader were to visualize the structure of the planet Saturn as it relates to the concept of family driven care, the model for family driven care includes a core “planet” (comprised of the critical partnership between the local family organization and system of care leadership); a magnetic force that originates from the core and illustrates the work of the family organization and system leaders to infuse the value of family driven care into the system; and rings, which orbit the core and depict system activities as well as developmental progression of family driven care as the rings expand outward.

This framework is intended to highlight what research findings show are the critical components specific to communities that have successfully engaged families in system level decision making. For example, although it is very important to have a family organization that supports and provides parenting classes for families, generally speaking, all family organizations view this as their mission—not only ones in communities with family involvement at the system level. However, a family organization that coaches and role plays with a parent to advocate for him/herself in a meeting with a provider then in turn works with the provider to model strengths-based interactions with the family is a strategy that appears unique to these systems. As such, the framework highlights these unique activities.

**Core.** The core of this framework includes three critical components: a family organization, system of care leaders, and a close partnership between these two entities, as described below.

**Family Organization.** This family organization has several important characteristics. As described in the first key finding, the family organization is politically independent. It is financially autonomous or is working toward financial autonomy with
the encouragement of system of care leaders. The organization is locally grown and has multiple paid staff to meet the numerous training, coaching, mentoring, and advocacy needs of families within the community. The family organization is well structured, with leaders and staff who understand the business aspects of running an organization and are always looking to build capacity by expanding their own skills but also identifying families within the community to become future training and leaders.

*System of Care Leaders.* Having *at least one* leader within the system of care, external to the family organization, who genuinely values family driven care at the system level and “champions” family involvement is critical to infusing this value within the system. Within system of care leadership, this effort is often initiated by an administrator within the mental health but broadens to other leaders within the system. Some agencies will likely have more buy-in into the concept of family driven care than others, but system leaders who value family driven care will heavily promote this value with leaders and staff of the other agencies. They do this by continually articulating the value of family driven care and how the system benefits from family involvement, they model respect of families and inclusion of families in all aspects of system planning, implementation, and evaluation. They are constantly self-reflective in how they can improve family involvement within the system and strongly encourage all staff to do the same. Finally, these leaders view the success of the family organization as everyone’s responsibility within the system.

*Partnership.* A close working partnership between the family organization and system of care leadership is also a critical component of family driven care. This partnership is comprised of an ongoing, reciprocal strategic investment, in which both
parties contribute to the system of care. For example, system leadership may contribute by training members on how to conduct evaluations, and the family organization helps to sustain itself by contracting with system partners to conduct evaluations. However, the partnership also includes important elements such as joint planning, implementation, and evaluation of the system as well as other collaborative activities such as joint training and grant writing.

**Infusion of FDC (i.e., the “magnetic force”).** System of care leader(s) and leaders and staff from the family organization work to infuse family driven care into the system. This is an ongoing process in which they continually articulate the value of families in the decision-making process and constantly reach out to system partners to encourage inclusion of families.

**Orbital rings.** The rings that comprise the orbit illustrate two distinct but important components: 1) system activities, and 2) the developmental progression of family driven care.

**System activities.** Activities that occur across the system that facilitate family involvement are depicted in the bubbles on the orbital rings. They include activities that are primarily initiated by, but are not exclusive to, members of the family organization. These activities tend to be ones that occur at all levels of the system, whereas activities related to *Partnership* (within the core) are often initiated by leaders within the system. System activities within the rings depict activities that allow family driven care to more broadly permeate the system. **Training, coaching, and mentoring families** includes activities conducted by the family organization that helps to strengthen families’ skills and aid them in having positive interactions with agency partners. This includes not only
general support such as access to and information about resources and parenting classes, but also includes activities such as role playing with parents on conflict resolution and how to communicate what they need to providers. At the same time, the family organization is **communicating with agency partners**, sharing information and resources with them, positively interacting with them and developing rapport as they serve as a liaison between the agency partners and families. The family organization is also **modeling strengths-based interactions**, with a primary focus on modeling strengths-based interactions with families for agency partners but also modeling positive interactions with agency partners for the benefit of the families with which they are working. **Training and coaching agency partners** is another critical activity. Although training occurs in many systems, training within these systems includes topics that are specific to working in a strengths-based way with families and is supported by coaching (as well as modeling). Trainings are often carried out by members of the family organization or include families, who share their stories and experiences with agency partners, making personal connections between families and providers. The **relationship building** that occurs between agency partners is generally initiated by the family organization and goes beyond basic communication and information sharing. Members of the family organization make personal connections with agency partners, and trust develops between these agencies as they work as **partner** agencies to serve children and families. The family organization also engages in **capacity building**, identifying family members who can be developed into trainers, mentors, coaches and leaders within the organization and the system. Finally, throughout the system, **self-reflection/assessment** occurs. At the individual treatment level, formal assessments may be conducted on
family-centered practice and how extensively families are driving care at the individual treatment level. At the system level, although these assessments may be informal, stakeholders still examine how well families are being engaged in decision making at all levels of the system, and they seek ways in which the system can become more family driven.

**Developmental progression of family driven care.** Research findings reflect four developmental stages in communities that involve families in system level decision making, with an initial condition of a partnership between the family organization and system of care leadership. The four stages of Responding, Strengthening, Norming, and Transforming will be described within this section.

In communities with system level family involvement, the inclusion of families has been described as a long-term but deliberate process in which this shared value takes time to truly take root within the system. Stakeholders who embrace this concept are persistent, nurture this process, and acknowledge that the process of working towards family driven care is never considered complete; however, having a family organization and at least one system leader who values family driven care appears to be a critical initial condition. As these individuals work to infuse family driven care within the system, engaging in various activities, the system begins the first phase—**Responding**—meaning that as individual agency partners hear more about family driven care, have positive interactions with the family organization (and families they are coaching and mentoring), and begin to observe and experience the 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.
The second phase, **Strengthening** encompasses the idea that continued positive experiences between traditional agency partners and families and the relationship-building that results creates momentum for family driven care. Agency partners describe their positive experiences with the family organization (and the families they support) with their colleagues, and more partners begin to engage these individuals. Barriers (both physical and mental) that prevent families from being included begin to be removed. The **Norming** phase shows further permeation of families being involved 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 even stop meetings without family representation. The fourth phase, **Transforming** reflects a system that has become family driven, with families having a primary decision-making role in planning, implementing, and evaluating the system.

**Summary.** An examination of the final framework in comparison to the Frameworks 1 and 2 reveals both similarities and differences. The most notable differences are reflected in important partnership between the family organization and the system of care leaders and the ongoing activities they engage in to infuse family driven care into the system, with the family organization initiating many of these activities.

The aim of Chapter Four was to describe research findings related to this study’s four core questions. These findings were based on a secondary analysis of qualitative data collected during *Case Studies of System Implementation* as well as primary data collected during the conduct of focus groups for the purpose of obtaining feedback on a framework for implementing family driven care within system of care communities. Chapter Five of this dissertation will discuss implications of the framework and synthesis of findings.
from research questions 1 through 3. Chapter Five will also examine the feasibility of using a rubric to assess the implementation of family driven care and will provide next steps for future research.
Chapter Five: Discussion

Chapter Four offered findings related to structures, processes, relationships, and values that are characteristic of family involvement in system level service planning and delivery decisions. It also provided findings related to the factors that facilitate and impede the mandate of family driven care and offered a framework for implementing system level family driven care. The purpose of this final chapter is to provide overall discussion points related to these findings and an examination of the feasibility of developing a rubric for assessing family driven care. Strengths and limitations of the study as well as future research directions will also be offered.

Implications for Family Driven Care

Structures and processes are necessary but not sufficient. Study findings indicate that communities that engage families in system level decision making invest in developing structures, processes, relationships and values in their systems. In the field of mental health, the current investment in family driven care as well as broad system of care development primarily focuses on improving structures and processes, with less emphasis on building relationships and attempting to infuse values into the system. For instance, the Cooperative Agreement for CMHI describes structural components such as governing body membership to include the Lead Family Contact and funding support for families participating in system of care planning and implementation. This is not
surprising, as it is difficult if not impossible to dictate the development of relationships or
the infusion of values. It is equally challenging to measure success of implementation of
these somewhat nebulous concepts. However, it is important to note that research
findings from this study as well as current literature support moving beyond structures
and processes. For example, Osher, Osher, and Blau (2006) note the importance of
funding support, membership of families on governance bodies, and sharing of resources
and information but further emphasize the importance of ensuring that family and youth
voices are heard and valued. DeChillo and colleagues (1994) and Osher Penn, and
Spencer (2008) similarly note strategies that are more structural and process in nature but
also emphasize the importance of relationship building, which is further supported by the
work of Duchnowski and Kutash (2007) as well as the National Federation of Families

Findings indicate that whereas sites with system level family involvement show
evidence of structures, processes, relationships, and values, systems without family
engagement at the system level primarily show evidence of structures and, to a lesser
degree, processes (e.g., an unfilled position or token representation in which families may
be asked their opinions but their ideas are not seriously considered by other members of
the board). In sites with system level family driven care, if one were to take the
characteristic of membership on a governing body and consider evidence in each of these
categories, the structure of membership on this governing body concretizes a family
organization’s roles and responsibilities and is evident in organizational charts and
meeting minutes. Evidence of processes might include that members of the family
organization actively participate, offer ideas, have those ideas considered and
implemented. Evidence of relationships might include when members of the family organization are genuinely welcome in a meeting—i.e., other members check to make sure they will attend, other members make small talk with them before and after the meeting, families feel respected when they speak, eye contact is given, and seating at the meeting shows co-mingling of families and agency partners. Evidence of values is reflected in leaders promoting the importance of family driven care. It is worth noting that this includes much more than just “talking the talk” but modeling inclusion of families, prioritizing the engagement of families and agency partners holding themselves and each other accountable for including families. There is a shared expectation that families will be included because they should be helping to make decisions about services and supports for children with SED and their families throughout the system. Without question, structure and process components related to implementing family driven care are easier to mandate and evaluate. However, findings from this study support the critical inclusion of relationships and values.

**Values are foundational to the inclusion of families.** Not only do research findings indicate that relationships and values are critical, but meaningful inclusion of families in system level decision making is ultimately driven by influential leaders who have embraced the value of family driven care and work to infuse this value into the system. As described in the literature review, the original system of care values have been expanded over the years to include family driven care (Stroul, Blau, & Friedman, 2010; Stroul, Blau, & Sondheimer, 2008; Stroul & Friedman, 1994). The originators of the concept argue that the system of care philosophy should never be considered independent of its values and guiding principles (Stroul & Blau, 2010; Stroul et al., 2010). The
emphasis on a values base of family driven care is present not only in the CMHI RFA (USDHHS, 2010) but also in numerous resource materials for current and potential system of care sites, whether digitally (http://systemsofcare.samhsa.gov) or in print (Stroul & Blau, 2008). This value provides the foundation for the successful integration of family driven care into everyday system planning and implementation (Baxter, 2010). Osher, Van Kammen, and Zaro (2001) describe sharing of values as a first step but the importance of moving beyond to changing behaviors. Without this value, systems may go through the motions of having families “involved,” for example, having a position on the governance board. This may even serve to satisfy a funding requirement. However, it is not a meaningful position that truly utilizes the expertise of families and works to improve services and supports within the system. The notion of a values base to guide system change related to family driven care aligns with literature on broad system development that contends that persuasive actions intended to shift values and beliefs of stakeholders within the system are critical for systems change; further, that these values are a critical early component in the systems change process and have the potential to guide other actions within the system (Hodges, Ferreira, & Israel, in press).

The presence of a family organization is essential to facilitate family driven care at the system level but not necessarily at the individual treatment level. Having a well-functioning, locally developed family organization that works in partnership with other agencies is necessary for system level family driven care. This finding, supported by the work of Hodges, Nesman, and Hernandez (1999), Lazear and Anderson (2008), and Osher, Penn, and Spencer (2008), is further supported by funding requirements.
through the CMHI (USDHHS, 2010) that emphasize the development and sustainability of a local family organization.

Although the triggering conditions for their system development varied greatly—from completely voluntary systems change efforts initiated by system partners with a similar vision, to grant funding, to a class action lawsuit—the systems with strong family involvement have partnerships with locally developed, independent family organizations. This is clearly evident in Sites 2, 3, and 5, where the family organization played a critical role in the early development of their systems of care and continues to have significant impact.

Although the secondary analysis showed considerable variability in the involvement of families in system level decision making, all six sites were chosen for the original study because of their exemplary work in providing needed services and supports for youth with SED and their families and demonstrating positive child- and system-level outcomes. Not all of these sites have a family organization that is an equal partner agency within the system. However, it should be noted that all sites within this study provide exemplary care for children and families within their communities.

**System implementers, not family organizations, are ultimately responsible for carrying out the policy mandate of family driven care.** It is important to note that the six communities that participated in this study began to develop their systems of care many years before the implementation of the mandate for family driven care, which became part of the CMHI mandate in 2005 (USDHHS, 2005). Because it was a completely voluntary effort, there were no external mandates delineating roles and responsibilities of stakeholders. As such, activities to effect change specific to family
driven care within these systems have been primarily initiated by the family organizations, and these organizations have taken responsibility for implementing family driven care within their communities. This effort, of course, includes an important partnership with at least one leader who has a long-term commitment to this value and demonstrates shared power in a traditionally hierarchical structure. This is a significant shift from “business as usual” in a field heavily influenced by professional guilds and licensure requirements. However the activities of the family organizations are particularly noteworthy. These individuals describe how they initiate outreach to develop positive relationships with agencies, how they train, coach and mentor families and how they model strengths-based interactions for agency partners, often serving as mediators between the agency partners and families.

The responsibility for implementing family driven care is not intended to be delegated to the family organization. The current federal mandate (USDHHS, 2010) clearly places the responsibility for carrying out this effort with system of care leaders while providing specific roles and responsibilities for the Lead Family Contact. An examination of literature specific to the development of family organizations within systems of care does not support this burden on the family organizations. Rather, the literature reveals a partnership between the family organization and other system partners (Koroloff & Briggs, 2003; Lazear & Anderson, 2008; Osher, Penn, & Spencer, 2008). Further, empowerment literature specific to this population does not describe a tipping of the scales in which the empowered individual actually assumes the majority of the responsibility, but rather describes strategies to improve parents’ self-efficacy, gain a sense of control over their lives, and—at most—have a balancing of authority in which
providers and families are viewed as equal partners (Dunst, Trivette, & Deal, 1989; Koren, DeChillo, Friesen, 1992; Singh et al., 1997; Sheer & Gavazzi, 2009). It is important to reiterate that the systems examined during this study began involving families in system level decision making before the CMHI RFA delineated specified requirements related to family driven care. Nevertheless, system implementers should pay careful attention to this balance to ensure that the family organization does not carry the burden of implementing the mandate.

**Capacity building for new family organizations is essential.** Study findings indicate the necessity of having an Executive Director of the family organization with the skills necessary for managing a non-profit organization. Leadership and management skills as well as grant writing appear critical. This finding is supported by research conducted by Koroloff and Briggs (2003), who describe family organizations as looking like a small social service agency as they develop. They note that these organizations often work toward non-profit status, create a system for tracking information including services and supports and accounting of resources. These activities are also emphasized by the work of the National Federation of Families for Children’s Mental Health (2004), and Osher, Penn, and Spencer (2008) who point out that leaders of family organizations may have no business experience but are expected to create and sustain an organization with a great deal of fiscal responsibility.

Surprisingly, findings indicate that it appears less critical that the Executive Director be the parent of a child or adolescent with mental health challenges. In systems with the strongest engagement of families in system level decision making, the vast majority of staff within the family organizations as well as board members of the family
organization meet the requirement of being a family member of an individual with mental health challenges—usually parents, but also siblings or spouses. It should be noted that although an Executive Director may not be a family member, these directors are very clear that their commitment is to the families served within the system and ensuring these families receive the support, advocacy, training, and coaching that they need to be successful. As one Executive Director notes,

*I know that there are people who look at me, “How can you run a family organization when you don’t, you have never walked that road.” I think I can do it just fine. Not all of my [family advocates] have children who have mental illness. I have to be really careful to make sure I listen to families and listen to them often.*

The emphasis on family driven care within systems of care mirrors that of cultural competence. An interesting observation made throughout the course of this study relates to the striking similarity between the advancement of the value of cultural competence and the family driven care movement. As noted previously, the original System of Care Values did not include either family driven care or cultural competence (Stroul & Friedman, 1986). In 1989 a CASSP Technical Assistance Center Minority Initiative Resource Committee developed a system of care monograph to specifically address the unique needs of culturally and racially diverse groups (Cross, Bazron, Dennis, & Isaacs, 1989). This served as an impetus for more targeted efforts to address the needs of these populations in systems of care.

As with family driven care, CMHI funding requirements related to cultural competence within systems of care have become an important component of the RFA. Although the initial RFA only required that communities provide services in a cultural context without discrimination, by 2002 communities were required to demonstrate a
focus on cultural competence in system level activities such as management planning, staffing, and project organization.

Current requirements related to cultural and linguistic competence very closely mirror those of family driven care, with a designated cultural and linguistic competence coordinator; composition of governing boards reflecting diverse populations; and full participation of culturally and linguistically diverse youth and families into service planning, implementation, evaluation, and sustainability activities (USDHHS, 2010).

These requirements are intended to enhance the multiplicity of voices within systems of care—not only of families and youth, but of families and youth regardless of race, ethnicity, culture, sexual orientation, age, or gender.

**Assessing the Implementation of Family Driven Care**

In systems of care, instruments to assess family involvement at the system level are few. The Family Empowerment Scale (FES) developed by Koren, DeChillo, and Friesen in 1992, is still used in its original form almost 20 years later. As a component of their evaluation, communities currently funded through the CMHI use the National Evaluation’s System of Care Assessment, which contains a few questions related to the role of families within the system. Beyond these instruments, communities resort to assessing system level family involvement using locally developed parent satisfaction surveys. Huff Osher Consulting, Inc. (2007) has developed a Family Driven Care and Practice System Self Assessment Tool for communities to assess readiness, infrastructure, and resources within their systems to support family driven care. However, this instrument, thus far, does not appear broadly used within systems of care. [It should also be noted that at the individual treatment level, instruments such as the Wraparound
Fidelity Index-4, Caregiver Version (Wraparound Evaluation and Research Team, 2007) capture useful information on family driven care specific to the treatment team process.]

Clearly the field lacks a current, comprehensive instrument to assess family driven care at the system level. However, development of this type of instrument is not without its challenges. The final framework presented in this study offers several components that were found to be important to the implementation of family driven care. Each component includes numerous parts that come together to create a whole. Each of these component parts may serve as indicators as to whether or not the component is being carried out successfully. If one were to examine one of the less complex components of the framework, *Training and Coaching Agency Partners*, each aspect of this component would need to be examined. Training alone includes consideration of the topics covered, location of trainings, who attends the trainings, who facilitates the trainings, not to mention the more difficult to assess components related to the climate of the training environment—whether, if families are included, they are made to feel welcome and as equal partners (and the number of indicators that might be associated with this concept such as seating arrangements, small talk before or after the training, family inclusion in discussions). The complexity inherent in this type of assessment may explain the lack of instruments currently available to assess family driven care. This is a significant challenge, however, as communities are being required to implement family driven care.

An overarching question becomes whether or not the development of some type of rubric to assess family driven care would be feasible and actually useful within system of care communities. A rubric, a commonly-used term in the field of Education, is a tool
that includes a set of criteria to assess progress toward learning objectives and can take many different forms—from checklists to tables with yes/no dichotomous responses or Likert-type scales with multiple anchors that might reflect low, medium, or high levels of implementation. Regardless of its structure, a significant amount of detail is needed to adequately assess each component. Conversely, at what point does a comprehensive assessment tool with such detail become unrealistic and virtually unusable?

An important component of qualitative research includes an iterative process in which data guide the researcher. This could not be more evident than in the process of framework development and exploration of the necessity to assess family driven care that has guided this research project. This study has led to this researcher’s membership on the National Federation of Families for Children’s Mental Health’s workgroup on Assessing Family Impact. The workgroup, using findings from this research study as well as experiences of stakeholders from systems of care currently funded through CMHI, has been charged with developing an instrument to assess family driven care. Importantly, the development of the tool will not be based on the individual perspective of this one researcher but will reflect a team-developed product based on collaboration between Lead Family Contacts, evaluators, and project directors of three systems of care, members of the Federation of Families for Children’s Mental Health, and this researcher as well as other ad hoc members. The group’s work continues, as it attempts to address some of the challenges described above.

**Limitations**

Because this study relied heavily upon a secondary analysis of data, questions during the original study were specifically designed to gather information on how the
systems implement family driven care. Nevertheless, data were plentiful; and not surprisingly, the most substantive data were provided by sites with strong family involvement at the system level.

In addition, for the purpose of data analysis for this study, the concepts of structures, processes, relationships, and values were clearly defined, and clear inclusion and exclusion criteria were used. However, the research team found that many of these concepts, particularly in systems that strongly demonstrate the infusion of the value of family driven care, overlap each other and are not discrete components as the coding might suggest. Data analysis did not accommodate for this type of overlap and the linkages that might occur between the components.

**Next Steps and Future Research Directions**

While this study has provided new information on the structures, processes, relationships, and values that play an important role in the implementation of family driven care, it also highlights critical next steps and several areas for future research. Next steps include the development of a guidebook, based on the new empirically-based framework, which will offer strategies for system of care communities aiming to move toward a more family driven model. In addition, it is important that work continue on developing a rubric with indicators to assess progress toward family driven care within systems of care. Development of formal instruments to assess family driven care at the system level is critical to the field. Although the framework presented within this dissertation includes self-reflection/assessment, such assessments at the system level are generally informal processes. As systems of care work toward more actively engaging families, it is critical that they have a means to *formally* assess progress. It is anticipated
that the role of assessment within the framework will become more prominent as communities begin these formal processes.

Areas for future research should be considered both methodologically and substantively. Methodologically, researchers should further consider how data are aggregated to develop findings for a unit of analysis that is as comprehensive as a system of care. Interview data were collected from individuals who were able to speak to the development and implementation of the system of care. These data were then aggregated and helped create a picture of how these systems developed. An exploration of how data from the individual perspective ascend to a system level unit of analysis is warranted. It is important to note, however, that this does not include attempts to force a cause-effect relationship between system level changes and clinical outcomes of youth. System level changes affect system level outcomes such as decreases in out of home placements, but attempting to create a direct link without accounting for the plethora of intervening variables is not advised.

Substantively, it is important to examine the use of the new framework and guidebook (to be developed) within system of care communities. The framework was designed with the intent to modify its components based on further research, as the field gains a better understanding of how the process of implementing family driven care actually occurs.

A second area of investigation includes developing and testing a rubric to assess family driven care based on the framework described within this study. As noted above, it is critical that this be a collaborative process that includes families of children with SED
who are being served within systems of care as well as administrators and practitioners who work within systems of care.

Further examination of culture within the six participating sites is also warranted. Two types of culture should be considered: cultural competence, and organizational culture. Within systems of care, funders and policy makers use a narrow definition of cultural and linguistic competence. It should be noted that in these systems, culture is not only recognized within the more traditional race, ethnic, culture paradigm but more broadly includes sub-cultures such as those specific to particular disciplines. For example, child welfare has a culture that traditionally does not include families in decision making. Culture in education reflects a completely different set of mandates around identifying and providing services for youth with SED. Within these sites, system stakeholders’ sensitivity and response to many different sub-cultures is notable and worthy of further exploration. In addition, if one considers organizational culture more broadly, data reflect significant shifts in the culture of each system of care as a result of their overall systems change efforts. These cultural shifts are worthy of further examination.

Finally, in the field of children’s mental health, research continues to focus on individual child and family outcomes related to the role of families in decision making processes at the treatment level. System level outcomes such as reduction in the number of out-of-home placements, reduction in costs, and issues of sustainability in systems implementing family driven care warrant further examination. Furthermore, the impact of advocacy processes at both the individual treatment and system levels should also be explored. Current research includes an examination of family advocacy organizations and
the important role of families in educating others in a peer-to-peer format (for example, Hoagwood, 2008; Kutash, Duchnowski, Green, & Ferron, 2010). An investigation is needed to examine how advocacy processes at the individual treatment level and peer-to-peer support activities at the system level may work together to create effective services for children with SED and their families.
References Cited


Comprehensive Services Act (1992), Code of Virginia, §2.2-5200 and §2.2-5212.


Lazear, K., & Anderson, R. (2008). *Examining the relationship between family-run organizations and non-family organization partners in systems of care*. (RTC Study 6: Family organizations and systems of care series, 244-3). Tampa, FL:


experiment in rural services integration in Franklin County, MA. *Alcoholism Treatment Quarterly*, 22(3), 19-39. doi: 10.1300/J020v22n03_02


Appendices
Appendix A: Number of Interview Respondents by Role per Site

<table>
<thead>
<tr>
<th>Site</th>
<th>Family Member/Advocate</th>
<th>Youth</th>
<th>Service Provider</th>
<th>Service Manager</th>
<th>Evaluator</th>
<th>Administrator/Policy Maker</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>9</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>8</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>0</td>
<td>26</td>
<td>15</td>
<td>8</td>
<td>31</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>0</td>
<td>14</td>
<td>9</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>1</td>
<td>9</td>
<td>10</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
<td>0</td>
<td>4</td>
<td>12</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
<td><strong>2</strong></td>
<td><strong>62</strong></td>
<td><strong>63</strong></td>
<td><strong>18</strong></td>
<td><strong>88</strong></td>
</tr>
</tbody>
</table>

*Family Member or Advocate:* Individuals representing/supporting the family perspective. This also includes directors of the family organization, who have administrative functions but view their roles as family members or advocates as their predominant roles within the system. These may have paid or unpaid positions within the system.

*Youth:* Youth over the age of 18.

*Service Provider:* Case/care managers, therapists, psychologists, physicians, nurses, teachers, probation officers, and attorneys. These individuals provided formal services and supports to the child and family within the system. This also includes therapists who have some supervisory duties within a program but also carry caseloads.

*Service Manager:* Program managers and directors (middle managers), trainers, special education supervisors who reported to the special education director.

*Evaluator:* Internal or external evaluators. May also provide technical assistance (e.g., Universities, consultants), and often have an administrative role.

*Administrator or Policy Maker:* System level administrators, funders, policy makers, judges, system partners involved in upper-level decision making.
Appendix B: Interview Guide for Case Studies of System Implementation

Semi-Structured System Implementation Interview Guide
Study 2: Case Studies of System of Care Implementation

Name of Interviewer: __________________ Date and time of interview: __________________
Participant: __________________________ Agency/Program: _________________________
Position: __________________________ Position: __________________________
____ Agency  ____ Program  ____ Community __________________________
Phone: __________________________ Phone: __________________________
Fax: __________________________ Fax: __________________________
Email: __________________________ Email: __________________________

Please attach respondent’s card if available.

Introduction
We are in the initial months of a 5-year study titled “Case Studies of System Implementation” that is part of our Research and Training Center for Children’s Mental Health. The study is focused on identifying and understanding factors that affect system implementation in communities that have successfully implemented systems of care.

We are particularly curious about how system implementation happens, because even though systems of care have been developing for 20 years and there have been some great results, we still don’t know what exactly makes this happen—why some systems survive and thrive while others don’t.

We are interested in hearing your perspective because your system is an example of a system that has survived and thrived…it is a success story. We are hoping to figure out what has made it possible for it to be so successful.

In order to identify the specifics that are related to success, all of the questions in this interview relate to your experience with the development or implementation of your local system of care. Do you have any questions before we begin?
Appendix B (Continued)

Informed Consent
As part of the University process, we must have the consent of each participant before we conduct an interview. Although your system of care has consented to participating, we need your individual consent.

Before the interview begins, provide the participant with a written description of the study and explain the purpose of the study. Review the informed consent process and ask the participant to sign the consent (or to provide verbal consent for telephone interviews). Be sure:

1. The participant understands the voluntary nature of participation
2. The participant understands that we would like to tape record interview
3. Ask Respondent: “Are you willing to participate in this interview and have it taped?”

Interview questions appear on the back of this page.
Appendix B (Continued)

Questions: *(Interviewer to take notes on separate paper)*

**Historical Development of System of Care**

1) Please tell me a little bit about the history of your system of care and your role in the process of developing or implementing it.
   - Initial context
   - Triggering conditions
   - Identifiable change agents
   - Foundational strategies
   - Mid-course changes or realignments

2) How would you describe the population of children and youth with serious emotional disturbance and their families in your community?
   - Clear identification of who the system is intended to serve
   - Issues of context or need specific to this community
   - Change over time

3) What goals does your system have for this population?
   - System of care values and principles
   - Change over time

**Identification of Factors Affecting System of Care Implementation** *(these questions will be modified to reflect responses received from the online brainstorming and factor rating exercises)*

4) What strategies have been used to develop a system of care that can serve the needs and achieve its goals for children and youth with serious emotional disturbance and their families?
   - Fundamental mechanisms of system implementation
   - Structures/processes related to networking, access, availability, administrative/funding boundaries
   - Center’s identified factors
   - Participant’s role or contribution

5) What strategies do you think have most affected the implementation of your system of care?
   - Clear definition of the named factor from perspective of participant
   - Center’s conceptualization of factors
   - Articulation of why this factor has had such an effect
   - Participant’s role or contribution

**Relationship among System Implementation Factors**

6) How have staff and stakeholders been involved in implementation of your system of care?
   Are there certain groups of staff and stakeholders that have been key to the process?
   - Collaboration across agencies
Appendix B (Continued)

- Leadership
- Governance
- Direct service
- Family involvement
- Evaluators

7) Do you think any of the strategies you identified were more important or fundamental than others?
   - Remind participant of factors he/she has identified

8) Do you think the strategies you identified worked best because they happened in a certain order?

9) Are there strategies that worked best in combination with other strategies?

10) How has the process of system implementation been communicated to staff, stakeholders, and the community?

11) What would you change about the process of implementing your system if you could do it again?

12) What strengths and successes do you associate with implementing your system of care?

13) What challenges do you associate with implementing your system of care?
   - Conditions that impede system development
   - Strategies designed to meet the challenges

14) What kinds of information do you get about how the system of care is performing and how do you use it?
   - Achievement of system goals and outcomes

15) Describe any mechanisms that have been developed to sustain your system of care.

16) Is there someone else who would be important for us to talk to, to help us understand the implementation of your system of care?

17) Is there anything you would like to add to this interview?
### Appendix C: Codebook

<table>
<thead>
<tr>
<th>CODE</th>
<th>DEFINITION</th>
<th>INCLUSION CRITERIA</th>
<th>EXCLUSION CRITERIA</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structures</td>
<td>Specified roles, responsibilities, and authorities that denote organizational boundaries and enable an organization to perform its functions</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Structures-Facilitators | Structures that facilitate meaningful involvement of families at all levels of the system | Apply this code to all references about specific roles, responsibilities or authorities that are inclusive of families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care | 1. Do not apply this code for system procedures that may relate to families as full partners (see PROC), or for relationships (see REL) that may relate to families as full partners  
2. Do not apply this code for system structures that impede family involvement (see STR-IMP) or structures that appear to have no effect family involvement (see STR-NEU) | EXAMPLE: “We sit on many, again, team councils. [Name of advisory board with mental health]. Different types of, you know, meetings. We have the State Mental Health Council. We have another one there. We have on the Developmental Disability Council; we have one there. So, we have ‘em spread out all over….And, we’re representing (unintelligible). Again, the voice and, you know, trying to be equal partners.” (Site 3 FM) |
### Structures-Impediments

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Example 1</th>
<th>Example 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>STR-IMP</td>
<td>Lack of structures that facilitate meaningful involvement of families, or structures within the system of care that create barriers to involving families at all levels of the system</td>
<td>(family membership on the governing board) “[Name] is the county’s collaborative governing board for youth and family services consisting of the Juvenile Courts, Probation Department, Department of Health and Human Services and Placer County Office of Education” (Site 1 governance board guidelines)</td>
<td>“I think we’re trying to include more family and youth involvement. And that’s still a relatively… even though [name] has been our parent partner for 6 years, she’s our only parent partner…We’ve been struggling to have a family advocate part of our system, I would say for the last 8 years.” (Site 1 SM)</td>
</tr>
</tbody>
</table>

### Structures-Neither

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Example 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>STR-NEU</td>
<td>Structures within the system that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
<td>Family membership on an individual treatment team (not system)</td>
</tr>
</tbody>
</table>
### Processes

Methods and procedures for carrying out organizational activities and often involving sequences or sets of interrelated activities that enable an organization to perform its functions.

<table>
<thead>
<tr>
<th>Processes-Facilitators</th>
<th>PROC-FAC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processes/activities that are occurring within the system that facilitate meaningful involvement of families at all levels of the system</td>
<td>Apply this code to all references related to processes that support the inclusion of families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care</td>
</tr>
</tbody>
</table>

1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for relationships (see REL) that may relate to families as full partners.

2. Do not apply this code for system processes that impede family involvement (see structures that facilitate family involvement (see STR-FAC) or system structures that impede family involvement (see STR-IMP)).

<table>
<thead>
<tr>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>And communication is a different issue and…this is my best communication story. Is that in [town], all the schools and the parents were butting heads. And there was no communication. And if…a million times in that first few months, the parents would come and they’d say, “I hate that Teacher. I’m gonna shoot her. I’m gonna shoot her. I’m going there and I’m gonna kick her ass.” They would say that all the time. And I would be, like, “Okay. And what will that get you?” And one of the things...</td>
</tr>
</tbody>
</table>
we did in communication is we trained them to go to school and advocate for their kids and not listen to the other stuff around them. So that they could be…

[Interviewer] And not react to it.

[Respondent] Right. And not react to it. And I would say, “What’s your goal? Your goal is to get what you need for your child. Those people are not important to you. They’re not important to you. They don’t have to like you. You don’t have to be their friends. You just have to keep going. And you have to talk to them respectfully. You have to not say, ‘You never do your job.’ You have to, you know, there are things you can say, there are things you can’t say.” And, so, we would go to meetings with them, model it, and then I would actually do, like, sessions there, you know, in the middle of a group when somebody would get up like that, I would say, “Boy, that’s good to vent. Now how are we gonna fix that ‘cause you can’t go into school like that, right?” And, so, in terms of communication our parents have learned how to be advocates in ways they never thought they would. (Site 5 FM)

<table>
<thead>
<tr>
<th>Processes-Impediments</th>
<th>PROC-IMP</th>
<th>PROC-IMP) or processes that appear to have no effect on family involvement (see PROC-NEU)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROC-IMP</td>
<td></td>
<td>we did in communication is we trained them to go to school and advocate for their kids and not listen to the other stuff around them. So that they could be…</td>
</tr>
</tbody>
</table>

1. Lack of evidence of processes that facilitate meaningful involvement of families, or

Apply this code to all references related to processes that exclude (whether intentionally or unintentionally)

1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for

During a probation/mental health retreat, which included strategic planning for a particular initiative, no families were present. Notes from the retreat state: “A redesign subcommittee has already determined that
2. Processes occurring within the system of care that create barriers to involving families at all levels of the system

<table>
<thead>
<tr>
<th>Processes- Neither (Neutral)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROC-NEU</td>
</tr>
<tr>
<td>Processes within the system that neither facilitate nor impede meaningful involvement of families at all levels of the system</td>
</tr>
<tr>
<td>Apply this code to all references related to processes within the system of care that appear to have no effect on the inclusion of families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care</td>
</tr>
</tbody>
</table>

| 1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for relationships (see REL) that may relate to families as full partners |
| 2. Do not apply this code for system processes that facilitate family involvement (see PROC-FAC) or processes that impede family involvement (see PROC-IMP) |

| youth and parents will both be involved in the placement screening committee meetings” Note that this decision was made about families and youth without any present. Subsequent notes from the screening committee meetings (which meets 2X weekly) show no family or youth participation, even 3 months later. This is supported by an interview respondent who lists all members of the committee during an interview (Site 4) |

| A family organization holds a back-to-school family fun night |

| 189 |
### Appendix C (Continued)

<table>
<thead>
<tr>
<th>Relationships</th>
<th>Trust-based links creating connectedness across people and organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationships-Facilitators</strong></td>
<td>Relationships among system stakeholders that facilitate meaningful involvement of families at all levels of the system</td>
</tr>
<tr>
<td>REL-FAC</td>
<td>Apply this code to all references related to relationships among system stakeholders that facilitate inclusion of families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care.</td>
</tr>
<tr>
<td></td>
<td>1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for processes (see PROC) that may relate to families as full partners</td>
</tr>
<tr>
<td></td>
<td>2. Do not apply this code for relationships among system partners that impede family involvement (see REL-IMP) or relationships that appear to have no effect family involvement (see REL-NEU)</td>
</tr>
<tr>
<td><strong>Relationships-Impediments</strong></td>
<td>1. Lack of evidence of relationships that have developed across system stakeholders that facilitate meaningful</td>
</tr>
<tr>
<td>REL-IMP</td>
<td>Apply this code to all references related to relationships among system stakeholders that do not support (whether intentionally or unintentionally)</td>
</tr>
<tr>
<td></td>
<td>1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for processes (see PROC) that may</td>
</tr>
<tr>
<td></td>
<td>EXAMPLE 1: &quot;And you know the amazing part is, if they had listened to her like I did, they would know that there's nothing wrong with her. You're just not taking the time to listen to this woman. No, she's from Asia. So maybe she doesn't comprehend things like we do.&quot; She's (unintelligible). She can</td>
</tr>
</tbody>
</table>

Yeah, I mean we had people from [mental health] come to our conference and the engagement of system of care partners in their conference. And, we do every year. And, they’re not getting paid to come and spend that time with us. I mean, they’re just… they’re involved. And, they’ll actually come to, sometimes if we have a workshop of some sort, we’ve actually had them stop by to see… you know, so that they could see what families say. I think that’s a big part of it. I mean, there’s just the commitment made to families. (Site 3 FM)
### Appendix C (Continued)

| Relationships-Neither (Neutral) | Relationships among system stakeholders that neither facilitate nor impede meaningful involvement of families at all levels of the system | Apply this code to all references related to relationships among system stakeholders that appear to have no effect on the inclusion of families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care. | 1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for processes (see PROC) that may relate to families as full partners.  
2. Do not apply this code for relationships among system partners that facilitate family involvement (see REL-FAC) or relationships that impede family involvement (see REL-IMP). | System of care families are strongly linked to the Partnership for a Drug Free America. |

1. Do not apply this code for system structures that may relate to families as full partners (see STR), or for processes (see PROC) that may relate to families as full partners.  
2. Do not apply this code for relationships among system partners that facilitate family involvement (see REL-FAC) or relationships that impede family involvement (see REL-IMP).
### Appendix C (Continued)

<table>
<thead>
<tr>
<th>Value</th>
<th>An ideal accepted by an individual or group within the system that families should be full partners within the system of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value-Facilitators</td>
<td>The ideal accepted by an individual or group within the system that families should be full partners within the system of care</td>
</tr>
<tr>
<td>VALUE-FAC</td>
<td>The ideal accepted by an individual or group within the system that families should be full partners within the system of care</td>
</tr>
</tbody>
</table>

- **Apply this code to all references related to foundational values or beliefs that guide system stakeholders to include families as full partners in decision making in the care of their own children as well as the policies and procedures governing care for all children in the system of care.**
- **Do not apply this code for system structures (see STR), processes (see PROC), or relationships (see REL) that may relate to families as full partners.**
- **Do not apply this code to references of values or beliefs among system partners that impede family involvement (see Values-IMP).**

### Example 1:
“Because with leadership you will get the partners to the table. You’ll get those family organizations as well as government. I think we really have to have strong leadership with a will to communicate the shared values and goals of the community. Because sometimes the community doesn’t even know what the possibilities are.” (Site 5 Adm)

### Example 2:
[The SOC] is very fortunate in that they have valued the family organization. When I go to the state Federation meetings with other family groups from the rest of the state, I really realize the... how well I am treated here compared to how well they are treated and how well my organization is treated and respected and I use this term maybe not in the sense you think of, we are honored. (Site 5 FM)

<table>
<thead>
<tr>
<th>Value-Impediments</th>
<th>Lack of evidence of the shared value of families as partners within the system, or beliefs that contradict the value of family-driven care, i.e., inclusion of families as full partners in decision making in the care of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>VALUE-IMP</td>
<td>Conflicting values that create a barrier to involving families as full partners at</td>
</tr>
</tbody>
</table>

- **Apply this code to all references related to foundational values or beliefs that contradict the value of family-driven care, i.e., inclusion of families as full partners in decision making in the care of children.**
- **Do not apply this code for system structures (see STR), processes (see PROC), or relationships (see REL) that may relate to families as full partners.**
- **Do not apply this code to references of values or beliefs among system partners that impede family involvement (see Values-IMP).**

### Example 1:
Historically, is that you have leadership in the front, and family voice is an afterthought. So the leaders, kind of in their grandiose thinking, is “We are the leaders, we know everything, we’re going to do it this way.” That hierarchy of power. And they put themselves first, with a great idea, but they aren’t delegating their power and authority often, is what I’m seeing. (Site 1 FM)
| all levels of the system | their own children as well as the policies and procedures governing care for all children in the system of care | code to references of values or beliefs among system partners that facilitate family involvement (see Values-FAC) |
Appendix D: Focus Group Recruitment Flyer

VOLUNTEERS NEEDED FOR RESEARCH!
(Research Study: eIRB#2454)
The Department of Child and Family Studies, College of Behavioral and Community Sciences at the University of South Florida is seeking participants for a research study examining the implementation of family driven care within system of care communities.

Actualizing Empowerment: Developing a Framework for Partnering with Families in System Level Service Planning and Delivery examines the roles of families in service planning and decision making at the system level within systems of care. This study seeks to identify the core components and strategies used within systems of care to successfully engage families as full partners in system-level decision making. The study will:

- Examine structures, processes, and relationships that are characteristic of family involvement in system-level service planning and delivery decisions within established systems of care
- Identify factors that support and impede implementation of family driven care in established systems of care
- Result in a theoretical framework for implementing family driven care within a system of care

Who?
Lead Family Contacts, Principal Investigators, and Project Directors from systems of care that are currently funded through the Comprehensive Community Mental Health Services for Children and Their Families program (the Children’s Mental Health Initiative; CMHI).

A total of 20 volunteers are needed!!!

What?
2 focus groups—

10 participants are needed for each group
- 1 focus group with CMHI Lead Family Contacts
- 1 focus group with CMHI Principal Investigators and Project Directors

Where?
National Federation of Families for Children’s Mental Health Conference, Hyatt Regency, Atlanta, GA. (Rooms TBA)

When?
Focus group with Lead Family Contacts: Thursday, November 4, 2010 from 1:00-2:30 pm
Focus group with Principal Investigators and Project Directors: Saturday, November 6, 2010 from 7:00-8:30 pm

A $20 gift card will be offered to each research participant.

Criteria for Participants:

- Currently serving in the role of CMHI Lead Family Contact, Principal Investigator, or Project Director
- Within a currently funded system of care community (through the Children’s Mental Health Initiative)
- Have knowledge of strategies for engaging families as full decision-making partners within their system of care (can speak to what works and doesn’t work in engaging families)
- Can link this knowledge to specific examples within their system of care

It is expected that the framework developed from this study will assist systems of care in more effectively including families as full partners in system-level service planning and delivery decisions.

For more information about this study or to participate in one of the focus groups, please contact:

Kathleen Ferreira, MSE
Department of Child and Family Studies
Louis de la Parte Florida Mental Health Institute
813-974-4651 ferreira@usf.edu

USF University of South Florida
Appendix E: Informed Consent

Informed Consent to Participate in Research
Information to Consider Before Taking Part in this Research Study

IRB Study # 2454

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:
Actualizing Empowerment: Developing a Framework for Partnering with Families in System Level Service Planning and Delivery

The person who is in charge of this research study is Kathleen Ferreira. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Albert Duchnowski.

The research will be conducted at the National Federation of Families for Children’s Mental Health Conference in Atlanta, GA, November 4-7, 2010.

Purpose of the study
The purpose of this study is to:
• Examine the roles of families in service planning and delivery decision through an analysis of the structures, processes, and relationships that support and impede family involvement in system level service planning and decision making in established system of care communities and to develop a framework that describes core components for engaging families in system level decision-making.
• This study is being conducted as part of a dissertation, and a student is conducting this research.
Appendix E (Continued)

**Study Procedures**
If you take part in this study, you will be asked to:

You will be asked to participate in a focus group. The focus group will take no longer than 90 minutes. The research will be conducted during the Federation of Families for Children’s Mental Health Conference, November 4-7, 2010.

The focus group will be audio recorded. Only members of the research team will have access to the audio recordings and the audio data will be maintained on the Principal Investigator’s computer, which is password protected and has a firewall. The data will be maintained for 5 years and will be deleted after that time.

**Total Number of Participants**
About 20 individuals will take part in this study at USF.

**Alternatives**
You do not have to participate in this research study.

**Benefits**
The potential benefits of participating in this research study include:
Findings will provide system of care communities with an increased understanding of strategies for successfully engaging families as full partners in system level decision making.

**Risks or Discomfort**
This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

**Compensation**
You will be offered a stipend of a $20 gift card.

**Cost**
There will be no additional costs to you as a result of being in this study.

**Privacy and Confidentiality**
We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, study coordinator, research nurses, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
Appendix E (Continued)

- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).

- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Kathleen Ferreira at 813-974-5583.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.
Appendix E (Continued)

Consent to Take Part in this Research Study
It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study ___________________________ Date ___________________________

Printed Name of Person Taking Part in Study ___________________________

Statement of Person Obtaining Informed Consent
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

• What the study is about;
• What procedures/interventions/investigational drugs or devices will be used;
• What the potential benefits might be; and
• What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization ___________________________ Date ___________________________

Printed Name of Person Obtaining Informed Consent / Research Authorization ___________________________
Appendix F: Focus Group Questioning Route

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

Focus Group Script and Questioning Route

(after all participants have completed informed consent process)

Hello, and thank you all for taking the time to visit with us today about implementation of family driven care in your system of care. My name is Kathleen Ferreira, from the University of South Florida. Assisting me is Leslie-Ann Pagan, also from the University of South Florida. We are here to get feedback on a framework that we recently developed at USF that aims to help SOC communities implement family driven care. You have been invited to this group because of your experiences as a Lead Family Contact, Principal Investigator, or Project Director within a system of care.

Before we get started, let’s run through some of the ground rules. We will record this group because we want to make sure we don’t miss important points that you make. Please remember that we ensure confidentiality of your responses, and no one aside from us will listen to these recordings. Because we are audio recording this group, it is especially important that people speak one at a time. When someone speaks, please listen carefully and be respectful of their opinions, even if you disagree. Let’s use only first names today. This is an additional way of ensuring confidentiality. Please put cell phones on silent mode, and if it is critical that you take a call, please step out of the room and return as quickly as possible when finished. We want this to be a comfortable experience for you, so please help yourself to refreshments. We would like this group to be conversational, so we encourage you to talk directly to each other—but again, please speak one at a time. My role tonight is to guide the discussion and to keep track of the time. Because we are time limited, I apologize in advance if I need to interrupt to move the discussion forward or to end the group.

We are going to go around the room, and I would like you to introduce yourself and answer the first question; but in general, I encourage you to speak up throughout the discussion whenever you want to add a comment. Do not feel that you must respond in a particular order. For the first question, please provide your first name, the grade level of your child receiving special education services, and answer this question: “What is your favorite thing about your position within your system of care?”

As I mentioned briefly before, we are here today to discuss a newly developed framework aimed at assisting communities in implementing family driven care within their systems of care. We know that families as full partners in decision making at all levels of the system (whether individual treatment, organization, or system) is critically important and is actually mandated within the systems of care funded through the children’s mental health initiative cooperative agreements. BUT during my research, I often hear and see how much communities struggle with this.
Appendix F (Continued)

This framework has been developed based on 2 things—currently literature on engaging/empowering families and other stakeholders, and an analysis of data that I collected during a studying in which we examined established SOCs. I’m going to spend a few minutes describing the framework then asking for feedback with some specific questions that I have developed. There are no right or wrong answers in this process, BUT I have one major request. It is important that your answer be grounded in what you have seen or experienced within your system that either support inclusion of families or create a barrier—grounding it in very specific real world experiences that you have had—good or bad. This will help us make very specific modifications to the framework that will really enhance its use. If you make a recommended modification to the framework, I will likely ask “Because…” and want you to provide a specific example of how something helped or created a barrier to family involvement. Please share your views, even if they differ from others, and we would like to hear negative as well as positive experiences and comments.

Any questions before we move on?

1. I want you to take a few minutes to review the framework. Because this is a framework, there is limited space in which to add a lot of detail, however, a description of each component will accompany the framework. Looking at this framework, at first blush what components don’t make sense and are there other words that would make more sense? Are there any that make you want to ask “What does this mean?”

2. Now we will dig a bit deeper, focusing more on connecting this framework to your experiences in SOC development. Based on your experiences in system of care development, what components of this framework belong? How so?

3. Which components don’t belong? How so?

4. Identify and describe components that seem to be missing.

5. How do you see a framework like this being used within your SOC, if at all?

6. Not only will a description of the components accompany the framework, but there will also be an outline of specific activities and performance measures for assessing successful completion of the activities. Knowing this information, are there other things that might make it more useful?

I want to thank you all for the time you have taken to provide feedback on this framework. This information will be used to make modifications to the framework. If you have any questions, here is my card. Please feel free to contact me by telephone or email. Thanks again for taking time from your schedules during this very busy conference!
About the Author

Kathleen Ferreira received her Bachelor’s Degree in Special Education and Master’s Degree in Educational Leadership from the University of Central Arkansas, Conway. She is currently employed in the Department of Child and Family Studies (CFS) in the College of Behavioral and Community Sciences at the University of South Florida. Kathleen is involved in several research and technical assistance projects within CFS. She is Co-Principal Investigator of New Communities System Development a project with the American Institutes for Research to develop materials and facilitate training and technical assistance for communities implementing systems of care. Kathleen is Co-Investigator for Phases VI, and VII of the CMHI National Evaluation with IFC Macro, specific to assisting communities in development and use of theory-driven logic models to build community capacity for system development. Kathleen is also Co-Investigator for a 4-year evaluation of the federally funded Healthy Transitions Initiative.

In addition to these projects, Kathleen serves as Education Director for Online Learning in Children’s Mental Health, which provides access to online courses for individuals working in systems serving the mental health needs of children, youth, and their families. Kathleen is also co-instructor of a Survey Course in Mental Health Planning, Evaluation, and Accountability.

Kathleen has extensive hands-on experience in the field of mental health, first as an educator, then a Director of Education and Program Director within a community-based mental health agency prior to joining the Department of Child and Family Studies.