

Examining the Relationship

BETWEEN

Family-Run Organizations & Non-Family Organization Partners



in Systems of Care

Winter 2008

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EXAMINING THE RELATIONSHIP BETWEEN FAMILY-RUN ORGANIZATIONS AND NON-FAMILY ORGANIZATION PARTNERS IN SYSTEMS OF CARE

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Introduction

Examining the Relationship between Family-Run Organizations and Non-Family Organization Partners in Systems of Care is a product of one of the five system of care studies at the Research and Training Center (RTC) for Children's Mental Health at the University of South Florida. These studies are being conducted over five years (2005-2009) to identify and examine critical implementation factors which support communities and states in their efforts to build effective systems of care to serve the needs of children and adolescents with, or at risk of, serious emotional and behavioral disturbances and their families.¹

This monograph is one of several products developed by Study 6: Examining the Role of Family Organizations in Developing Family Voice in Systems of Care, which focuses on how family voice and family-driven care, as represented and implemented through family-run organizations, contributes to effective systems of care. Other Study 6 products include (1) *A Quick Guide for Self-Assessment of Family-Run Organizations in Systems of Care*, a technical assistance tool for family-run organizations and their partners,² and (2) *The National Directory of Family-Run Organizations*, an interactive web-based resource. Another of the five RTC studies, *Financing Structures and Strategies to Support Effective Systems of Care*, also produced a family organization focused publication—Issue Brief 2: *Effective Strategies to Finance Family and Youth Partnerships*.³ All products are available at <http://rtckids.fmhi.usf.edu/research/study/cfm>.

Purpose of the Monograph

This monograph explores the relationships and strategies of family-run organizations and non-family-run organization partners in systems of care in developing family voice and implementing family-driven services. Family-run organizations, for the purpose of this study, are organizations whose leadership and majority of staff are family members and are focused on meeting the needs of children and youth with or at risk of serious emotional and or behavioral challenges and their families. Non-family-run entities, such as state and local government agencies and provider organizations, are defined by this study as those that have broader purposes and typically have not been family-run. Historically, there has been a power imbalance between non-family-run entities, which control resources and have formal decision-making authority, and family-run organizations.

This study explores these relationships and strategies within the context of key elements articulated in the research as essential to family voice and family-driven care. Two major premises, corroborated by the findings, underlie this study.

- The first is that family-run organizations play a critical role in ensuring family voice and operationalizing family-driven care.
- The second is that the quality of the relationship between family-run organizations and non-family-run organization partners has a major bearing on how effective family-run organizations can be in this role.

This monograph presents the strategies and realities of six family-run organizations and their non-family organization partners as they address a number of key elements of family voice in systems of care. The six family-run organizations are diverse in their history, geography, stage of development, funding and supports, staffing structures, and cultures. Yet, each of them has an expressed commitment to improving the lives of children and their families and welcomed the study's close examination of their organizations. Each family-run organization's representatives and non-family-run partner entities presented the strengths and spoke candidly of the challenges in their system-building relationship.

Study Methodology

SITE SELECTION

Family-run organizations selected for participation in this study were nominated by and selected through a review process by a committee composed of national and local family organization leaders, family members, and system of care consultants, technical assistance providers and researchers. For participation in the study, the committee sought a diverse representation of family-run organizations and considered a number of factors in their selection deliberations. These factors included: whether the family-run organization was a statewide or local organization; how long the organization had been in existence; whether the organization had a 501-c3 designation as a non-profit entity; the geographic location of the organization; the population of families and youth served by the organization; how the organization was funded and became established; and, the functioning of the organization within the state or local system of care. Table 1 presents characteristics of the six family-run organizations. The family-run organizations consenting to participate in the study agreed to host a two-day site visit, which included identifying and setting up key interviews with child serving agencies and organizations and coordinating and setting up focus groups with family members.

DATA COLLECTION AND ANALYSIS PROCEDURES

Data collection for the participating family-run organizations included on-site semi-structured key informant interviews. Key informants were identified by the family organization director and included family members being served by the system of care, family-run organization board members, family members employed by the family-run organization, lead representatives from mental health, child welfare, juvenile justice, education, providers, other identified system of care and community partners, and the family-run organization director.

The study uses a participatory action research approach, involving family-run organization staff and family members in all aspects of the research. The study method is based on a multiple case study design. The data collection and analysis utilizes qualitative methods. Data in this report are based on site visits conducted between March 2006 and May 2007.

DESCRIPTION OF FAMILY-RUN ORGANIZATION STUDY SITES

Table 1: Characteristics of Family-Run Organization Study Sites

Family-Run Organization (FO) Study Site	Age of Organization	Population Served, Area Served and Square Miles	Percent and Number of 0-18 Population in the State County or Tribe *	Budget	Size of Paid Staff	CMHS System of Care Status**	Current Source(s) of Funding
FO-1	20 yrs.	All families in the State 1,045 sq. miles	22.2% 237,009	\$700,000	10	Graduated & Current	Federal Statewide Family Network Grant; State Dept. of Education (IDEA); Federal IVB Child Welfare
FO-2	18 mos.	All families in the County 47 sq. miles	22.5% 135,258	\$407,183	6	Graduated State Grant No direct affiliation	Medicaid Admin. Funds State General Revenue
FO-3	2.5 yrs.	All Hispanic/Latino Families in the County 1,051 sq. miles	25.0% 63,453	\$0	0	Graduated	No funding; Volunteer staff; In-kind contributions from community
FO-4	6 mos.	All Native American Families in the Neighborhood & Tribal lands 1.2 - 72 sq. miles	(0-19 years) 57.6% 126 - 800	\$0	0	Graduated Circles of Care***	No formal funding; Volunteer staff; In-kind contributions from community and tribal government
FO-5	3.5 yrs.	All families in the County 1,729 sq. miles	28.9% 1,123,114	\$10,000	1 (part time)	Current	Federal SOC Grant** Volunteer staff; Statewide Family Network Grant
FO-6	6 yrs.	All families in the County 9,203 sq. miles	27.3% 1,028,698	\$900,000		No affiliation	Medicaid Provider Contract through county Managed Care Organization (MCO) Contracts with state agencies

* Percent and number of population 0-18, square miles is based on 2006 U.S. Census Bureau data, except FO-4, which is 2000 data and includes U.S. Dept. of Interior sources.

** Comprehensive Community Mental Health Services for Children and Their Families Program, Child, Adolescent and Family Services Branch, Center for Mental Health Services (CMHS), Substance Abuse Mental Health Services Administration (SAMHSA) awards states and communities up to \$9 million, up to 6 years to develop a system of care for children and youth with serious emotional and/or behavioral disabilities and their families.

*** CMHS Circle of Care grant program is designed to support federally recognized tribal governments and urban Indian programs for their efforts to design and assess culturally appropriate mental health service models for American Indian/Alaskan Native children with serious emotional disturbances and their families.

Organizing Framework

DEFINING FAMILY VOICE AND SYSTEM OF CARE

A premise of this study and of system of care principles is that establishing a strong family voice is an essential and central element for the building and sustaining of a family-driven, effective, and integrated system of care. Often a key element for ensuring strong family voice is establishing a strong family-run organization.⁴ The study explores the ways in which family voice and family-driven care are developed and sustained within systems of care, specifically through a family-run organization. This monograph addresses specifically the ways in which the relationship between the family-run organization and its non-family-run organization partner organizations has a bearing on the effectiveness of the family organization's role in building family voice.

Throughout this monograph, we refer to family voice. For us, the essential meaning of family voice can be found in the definition of family-driven, as posited by the National Federation of Families for Children's Mental Health:

*"Family-driven 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: choosing culturally and linguistically competent supports, services, and providers; setting goals; designing, implementing and evaluating programs; monitoring outcomes; and, partnering in funding decisions."*⁵

In 1986, Stroul and Friedman defined a system of care for children with emotional disorders. In addition, this seminal work articulated the core values and principles for a system of care. Stroul and Friedman 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 children and their families."*⁶

In the past two decades, as states and communities continue to build their systems of care to meet the needs of their children, youth and families, a broader definition has emerged to reflect the growing context of these efforts. In 2002, Pires articulated an expanded definition of a system of care as,

*"A broad, flexible array of effective services and supports for a defined, multi-system population that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, builds meaningful partnerships with families and youth at service delivery, management and policy levels, and has supportive policy and management infrastructure."*⁷

As you will see throughout this monograph, this current and expanded definition of system of care supports our focus on a diverse cadre of family-run organizations and their relationships with non-family-run partner entities.

Key Elements of Systems of Care with Strong Family Voice and Family-Driven Care

Having effective family-run organizations is considered an important strategy for facilitating an organized family voice to ensure the full participation of family members in all aspects of systems of care and to ensure that family-driven care is supported and sustained.^{8,9} Our study's *Quick Guide for Self-Assessment of Family-Run Organizations in Systems of Care* identified a number of key elements of systems of care with a strong family voice.¹⁰ This monograph looks at six key characteristics as they apply to family-run organizations and their relationships with systems of care.

The first key characteristic or element is: targeted resources are in place to support and sustain the development and growth of a family-run organization to ensure that families are partners in all aspects and at all levels of systems of care and in a variety of capacities.^{11, 12, 13, 14}

This key element asserts that evidence of the value of family partnership by the system of care must be visible throughout the operations of a system of care, including setting policies, developing programs, delivering services, and assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large.^{15, 16, 17, 18, 19} Our study sheds light on the relationship between system of care non-family partners and the family-run organization in promoting the value of family partnership and communicating this value throughout system of care components. For example, we explored whether there is a base level of support (financial, material, personnel, and/or strategic) provided by system of care partners for families to successfully develop and sustain their own family-run organizations. We asked whether there is funding and in-kind support from multiple and varied sources. Pires and Wood (2007) identify two key strategies for financing family and youth involvement at the policy and system management levels. These strategies are

- Contracting with a family organization for participation in policy making and system management, including payments of stipends and supports, such as child care, transportation and meals for family and youth participation at the policy and system management levels, and
- Financing training and leadership development to prepare families and youth for participation in policy making and system management.²⁰

The second key element of a system of care with strong family voice is: a family-run organization is actively encouraged and supported in seeking to recruit and engage diverse family and youth leaders,

and nurtures their development to interface effectively with the system of care in a variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves.^{21, 22, 23, 24}

Our study asked such questions as: How do system of care partners support the family-run organization in developing family and youth leaders? What particular strategies do system of care partners utilize to encourage and support family-run organizations in seeking to recruit, engage, and nurture a number of diverse family and youth leaders sufficient to interface

consistently and effectively with the system of care in a variety of capacities, including family members and youth who are representative of all groups served by the system of care? What particular strategies do system of care partners utilize to encourage and support family-run organizations to enhance the child and adolescent workforce so that it is more representative of the community it serves?

The third element of a strong family voice is: a family-run organization is encouraged and supported to help family members and youth operate in a peer support role to assist other families and youth in accessing the system, navigating systems, providing information and emotional support.²⁵ Our study examined peer support roles and arrangements with family-run organizations in systems of care and the policies and practices of system of care partners that encourage and support family-run organizations to operate in a peer support role.

The fourth element of family voice in systems of care is: a family-run organization plays a key role in ensuring families and youth have access to needed quality services.^{26, 27, 28, 29} Our study explored how systems of care partners encourage and support family-run organizations to help families and youth access the system and to meet the needs and requests of families and youth in their communities (e.g., legal advice about school suspension, medication questions, etc.). We also looked at how system of care partners support and encourage family-run organizations to assist families and youth to have direct connections and access to mental health providers and other child serving agencies.

The fifth element is: a family-run organization 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 to children and youth with mental health needs.³⁰ The study examined the commitment to collaborate between family-run organizations and the other child and family serving agencies.³¹ In addition, the study explored the relationship between family-run organizations and an increasing number of supporting organizations that provide financial and philosophical support.³² We looked at the types of working relationships that family-run organizations have with state and local agencies and the opportunities, challenges, and value-added associated with these working relationships.

The last key element is: a family-run organization is supported and encouraged to engage families and youth in changing policy.³³ The perspectives of families and youth on mental health and related policies are not only critical, but can also be distinguished from the perspectives of service providers, administrators, and policy makers.^{34, 35} Our study asked such questions as: What, if any, is the relationship between family-run organizations and system of care partners in engaging families and youth in policies through legislative strategies to focus on child and adolescent mental health needs? How are non-family-run system of care partners supporting family-run organizations to assist families and youth in participating in the legislative processes that impact their lives?³⁶ How does the relationship between family-run organizations and non-family-run organization partners fit within the context of family organizations' organizational development, such as described in Koroloff and Briggs (2007) *Key Components of Family Organizations Over the Life Cycle*.³⁷

Strategies, Realities, and Observations

This section describes ways in which the relationships between family-run organizations and non-family-run organization partners support key elements of family voice and family-driven care. Organizations are not static entities, and, thus, the relationships and issues presented here have no doubt changed. However, these were the strategies and realities described by the family-run organizations and systems of care partners at one point in time. Following the description of each site in relation to a key element of family voice, we have assigned an Implementation Partnership Rating, or IPR, from 1 – 5 to describe the strength of the partnership between the family-run organizations and the non-family run entities to operationalize the particular key element. An IPR of 5 represents full, meaningful implementation with specific, effective strategies in place, and an IPR of 1 represents marginal to no implementation with no specific, effective strategies in place. IPR ratings between 1 and 5 are along this continuum. These ratings are *not* meant to rate the organizations, but create distinctions about the strength and nature of the partnerships between the family organization and the non-family entities. The ratings also help to illustrate the nuances involved in full versus partial implementation of these key elements of family voice and the role of partnership, which, hopefully, will be instructive to developing family-run organizations as their system partners.

Implementation Partnership Rating (IPR)				
1	2	3	4	5
Marginal to no implementation with no specific, effective strategies in place	A few efforts at implementation have been made, but strategies are minimally effective	Some implementation is evident, with strategies somewhat effective	Current strategies are effective, but additional strategies are needed	Full, meaningful implementation with specific, effective strategies in place

Key Element 1

Targeted resources are in place to support and sustain the growth of a family-run organization to ensure that families and youth are partners in all aspects and at all levels of the system of care, and in a variety of capacities to create “family voice” and provide family-driven care.

STRATEGIES AND REALITY CHECK

Family Organization 1 (FO-1): Statewide Family Organization

- Already in existence as a non-profit, grassroots organization for several years, FO-1 received its first substantial funds through the federal CMHS Statewide Family Network grant in 1986. In 1990, FO-1 received funding as a core component of the federal Child and Adolescent Service System Program (CASSP) statewide grant. FO-1 was awarded funding again in 1993, when the state received a System of Care grant from CMHS, and a few years later through another federal system of care grant focused on juvenile justice;
- Is a partner in the most recent CMHS Positive Education Partnership grant;
- Has a budget of just under \$700,000, over twice as much as was funded six years ago;
- 89% of the budget comes from the state, primarily federal grants passed through the state. Other sources of funding include a Statewide Family Network Grant (\$70,000), State Department of Education/IDEA (\$35,000), and IVB Child Welfare;
- Receives funding through contracts from state and federal entities to conduct bilingual (English/Spanish) focus groups to help develop culturally and linguistically competent materials;
- Participates in state policy meetings and is present at state budget hearings;
- Is involved at a direct service level providing information and resources to families and service providers at community and statewide events and various meetings;
- Provides advocacy and support to families at child and family team meetings;
- Is contracted by the state to develop and conduct parent satisfaction surveys and focus groups to help assess service providers and develop programs;
- Provides support of the youth movement in systems of care with a youth group that continues to grow and be more involved at many levels of the state’s system of care, (i.e., statewide planning committees, community service activities, and informational workshops and presentations);
- Continually advocates for family partnership at all levels of the system of care, achieved both at the state’s invitation, as well as at the insistence of families;
- While providing support and individual advocacy for families, advocating at a state level for sound and effective policies, and remaining stable and true to its mission amidst an ever changing political climate, FO-1 must also continue to advocate for itself as an organization.
- Is at risk of reduced funding as the legislature meets to make decisions that will have an immediate and profound impact on all of the state’s children, youth and families.

IPR: 4 FO-1 has a substantial budget through federal grant partnerships and state funding to support family and youth involvement in policy, direct service, and evaluation level activities. However, the organization must continually advocate for family voice at the table; there are no strong requirements (e.g., legislation) in place for providers to utilize family members in direct service or family partner roles; continues to feel vulnerable to budget cuts; and is heavily dependent on federal grant dollars.

Family Organization-2 (FO-2): County-wide Family Organization

- Is one of 15 non-profit family-run organizations funded by the state's division of behavioral health through a combination of state mental health and child welfare general revenue and Medicaid administrative case management dollars as part of the statewide system of care initiative;
- Currently has a budget of \$407,183 (increased funds to include starting a youth group), from initial start-up funds of \$340,000;
- Funding supports six full-time staff from the community;
- Funding supports a "warm line," community outreach, education forums, speakers bureau, and, support group activities by providing childcare and food;
- Is part of a statewide alliance of family organizations with access to a family organization consultant identified by the state;
- Received additional state funds to develop youth partnerships;
- State charged all counties in the system of care to implement family/professional committees to ensure that family representation was present at every level of the system of care;
- The state's locally based care management organization is required to utilize the services of FO-2; FO-2 is supported to provide direct peer support services to families, through a contract with the state, with the county care management organization;
- Participates on a state mandated, family/professional partnership committee at the state level whose purpose is to ensure that family representation is present at every level of the system of care, family partnership committee is a subset of a quality assurance committee;
- Serves on a quality assurance committee;
- Family partnership is at a different level of development in each county throughout the state in part due to the county-by-county "roll out" strategy employed by the state system of care initiative;
- FO-2 has had starts and stops on its development with board development and restructuring of staff based on hiring criteria;
- State system of care support, development and implementation is impacted by changes in state leadership.

IPR: 4 FO-2 is involved at all levels of care—advocacy, direct service, policy and evaluation. It is being financed through "system dollars," i.e., more traditional funding streams that are more entrenched in the children's system, such as Medicaid, rather than through discretionary grant monies. However, there are no diverse funding sources, as the state is the sole source of major financial support.

Family Organization 3 (FO-3): County-wide Family Organization

- Several years into a countywide CMHS system of care grant, a local university helped develop a Latino family organization to respond to the needs of Latino families. The university designated an existing staff person, who is a family member, to serve as FO-3 director as part of her existing job responsibilities (there is an existing local Federation of Families chapter in the county);
- FO-3 receives occasional donations from businesses to offer incentives for families to participate in specific activities;
- The university provides minimal staff support through consultation as needed, but no direct funding;
- Is seeking funding through a variety of grants and resources, mainly at the national level where FO-3 feels it has been well received;
- Provides referral and system navigation services and supports to its families, many of whom are monolingual Spanish speakers;
- Relies solely on parents and natural helpers and other volunteers in the community, who have knowledge and experience about navigating the mental health service system, to provide support services to help other families who are seeking services for their children;
- Latino family voice is not well represented at most levels of the system of care, including setting policies, developing services and evaluating the system, mirroring findings from studies conducted ten years prior that the Latino voice is not often represented, mainly due to the challenges presented by language and cultural barriers.
- The director represents the organization at the provider level, but is not represented at the state level or in local policy meetings;
- Most system of care meetings are conducted in English only, and most family members from the organization are monolingual Spanish speakers;
- Would like to become its own organization; however, several local system of care entities believe that FO-3 should become a part of the local Federation chapter and not compete for resources or family membership. For example, one provider agency felt that as a small provider agency, it cannot contract with two family organizations, and will contract for parent advocates through the local Federation chapter in hopes that FO-3 will be part of the local Federation, and can therefore be a part of that contract;
- Has applied for local funding from a local children's taxing authority, but with a larger family organization already in existence, funding was denied. Tension exists as FO-3 feels that the Latino family voice is not adequately represented in the system of care.

IPR: 1 FO-3 is struggling to have its voice heard at every level of the system of care. It is struggling to develop partnerships with other system of care entities that will support its development, growth and involvement at all levels of the system. While the local university and business community provide some support, there is no meaningful financial support from system of care partners.

Family Organization 4 (FO-4): Neighborhood-Based and Tribal Community Family Organization

- A newly formed, neighborhood-based, grassroots group, FO-4 receives no funding.
- Is part of a community that had a CMHS Circles of Care grant program ten years ago, designed to support federally recognized tribal governments and urban Indian programs in their efforts to design and assess culturally appropriate mental health service models for American Indian/Alaska Native (AI/AN) children with serious emotional/behavioral disturbances and their families and reduce the high number of Native children who are sent to long-term residential facilities and to assist them in returning home. Other projects emerged that incorporate culturally appropriate interventions and the natural support system of the community to provide intensive case management for the enrolled children and their families with the long-term goal to assist each reservation with developing a culturally appropriate system of care to meet the needs of their families. Three years ago, the community engaged in a project through the *Improving Child Welfare Outcomes Through Systems of Care Demonstration Initiative Grant*, a five-year cooperative agreement between the U.S. Department of Health and Human Services (DHHS) Administration on Children, Youth and Families (ACYF) and the Native American Training Institute (NATI), in partnership with the four tribal child welfare agencies in the state. The Tribe has also been awarded various grants to help stimulate economic growth and community development.
- The Tribe is governed by an elected Tribal Council comprised of nine members;
- FO-4 emerged out of the efforts of the child welfare initiative. An ad was placed in the local newspaper inviting anyone to come forward who was interested in forming a parent support group. There was one respondent, who lived in one of the tribal-owned housing projects. In the ensuing six months, the organization has grown to include 13-15 family members. FO-4 family members have begun to build partnerships with community businesses and rely heavily on these relationships to secure goods and services for various activities, such as a neighborhood clean-up. In addition, FO-4 has growing support from their Tribal Council.
- Family members have initiated dialog with their Tribal Council to obtain their support and have their voices heard about the needs of children, youth and families in their housing area;
- Provides peer support and plans and conducts community activities to raise awareness of their organization to begin to effect change;
- Family members do not participate in policy-setting or evaluation activities;
- Has support from an individual with a local child welfare federal grant, however, that person will no longer be funded to provide support when the grant ends;
- Local businesses and the Tribal Council provide in-kind support for various activities, such as the neighborhood clean-up day.

IPR: 2 The Tribal Council and child and family service entities are open to discussion of family issues, provided initial support for FO-4's development, and their continued support is evident through various FO-4 initiated activities. While family voice and leadership is coming from FO-4, with continued support (e.g., FO-4 as partners in grants obtained by the community), this could eventually develop into a meaningful partnership.

Family Organization 5 (FO-5): County-wide Family Organization

- Serves on governing boards and county committees working to restructure the system to improve the mental health and related services and supports for the county's children and families;
- Provides peer support for families;
- Monitors services;
- In existence since the county received a CMHS system of care grant sixteen months ago and is developing slowly and struggling to be a part of the system of care at all levels;
- Applying for not-for-profit status;
- Operates with a budget of less than \$1,000 per year from the state department of children and families through a Statewide Family Network grant to the statewide Federation of Families (which supports one of fifteen chapters throughout the state, serving 64 of the state's 254 counties) and a recently awarded county-wide CMHS system of care grant, which supports one part time paid staff person.

IPR: 2 FO-5 has only one source of funding – dollars from a small discretionary grant that is controlled by the larger family organization. Their work is primarily driven by the needs of families but has not translated into a true partnership with other entities within the local system of care grant community.

Family Organization 6 (FO-6): County-wide Family Organization

- Provides direct, Medicaid billable services to families in the county;
- Serves as policy and program advisor;
- Provides direct family support services;
- Provides training and community presentations on children's behavioral health issues;
- Conducts research and program or system evaluation (e.g., family satisfaction interviews, program data collection and analyses);
- Serves as members of behavioral health staff hiring panels;
- Strengthens the involvement of families by developing and providing training and support on new roles for families in their county's behavioral health system;
- Along with a statewide family organization, provides a strong family voice at the county and state levels, where policies are determined for the state's children and youth in need of behavioral health services;
- Began with a small grant from a local foundation. As the state moved towards a system of care framework and to managed behavioral health care, it was decided that family voice and partnerships with family organizations would be a key principle of the new system. The state and the county managed behavioral health care organization (BHO) invest significant resources in FO-6.
- Contracts with FO-6 are for \$900,000 for "system transformation" activities;
- FO-6 and the statewide family organization are at the state policy table and participate in discussions regarding the statewide development of the system of care;
- Through their contractual relationship with the county BHO and their Medicaid billable status, FO-6 provides a large number and variety of direct services to families;
- FO-6 is also directly involved in planning, conducting, analyzing and disseminating of evaluation and assessment activities for the system of care.

IPR: 5 Through contracts with multiple state agencies (e.g., mental health and child welfare), contracts with the county BHO, and its ability to bill Medicaid for direct services, FO-6 is supported by non-family-run system partners at all levels.

Key Element 2

Racially and ethnically and other culturally diverse family leaders are recruited and nurtured to interface consistently and effectively with the system of care in a variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves.

STRATEGIES AND REALITY CHECK

FO-1: Statewide Family-Run Organization

- Many providers rely on FO-1 for their ability and capacity to work well with families of color, recent immigrants, or families where English is not the primary language;
- As a network of diverse families, FO-1 views outreach to diverse families as primary to meeting its mission;
- Involved in information fairs, conferences, parenting meetings sponsored by other organizations, school fairs, hospital orientations, college and university student meetings, department fairs, resource directories, and juvenile justice activities;
- All material is translated into Spanish, hosts a Spanish support group, and has staff available to converse with families in Portuguese. FO-1 is collaborating with the state's international institute to assist refugees or recent immigrants in their life needs;
- Community outreach work includes a past sub-contract to look at police response to families in crisis and continues to develop a relationship with the police department in all the counties;
- Has a racially and ethnically diverse seven member board of directors, consisting of four family members and three professional members; a major challenge is to sustain a board with family membership at or above fifty-one percent;
- Board recently engaged in board leadership development training;
- As part of other federally and state funded initiatives, FO-1, and in some instances in partnership with other family organizations, is supporting the development of future family and youth leaders, through trainings and the provision of honorariums.

IPR: 5 FO-1 is viewed by the state, service providers and families as a front door to the system of care for many of the culturally diverse families in the state. FO-1 offers culturally and linguistically competent, multidimensional family leadership development (i.e., training, experience in leadership roles, networking opportunities).

FO-2: County-wide Family-Run Organization

- Serves a county with a large Hispanic/Latino population (about 41%) and thus much of their outreach efforts are focused toward this group;
- FO-2 is funded to hire six full time staff members from the community to ensure a staff that is representative of the community;
- As well as the strengths of FO-2's hiring of neighborhood-based staff, this also presented challenges, such as issues of trust and confidentiality and seeing neighbors in new roles.
- FO-2 is also supported to provide training to build the leadership capacity of families and youth throughout the diverse community.

IPR: 4 FO-2 is making inroads into their racially and ethnically diverse community, reaching families who have not been engaged with the system in the past. However, much more work needs to be done to create a local workforce that reflects the diversity of the community it serves and a system of care and provider network that offers parents leadership opportunities.

FO-3: County-wide Family-Run Organization

- Is encouraged, but has no direct support to build leadership from providers who refer Spanish-speaking families to FO-3;
- The providers inform family members about FO-3 and their potential as leaders in the community;
- Language is a major barrier to leadership development for families;
- Outreach to families and potential family leaders is challenging in the large county where many of the Latino families live;
- Currently, the executive director is the only visible representative from FO-3 at meetings in the community;
- There is little representation of Latino family leaders at the state level or with the county system of care.

IPR: 2 While the leadership of FO-3 is representative of the population it serves and is reaching out to the Spanish-speaking community, FO-3 receives no direct support to build diverse leadership within the organization.

FO-4: Neighborhood-Based and Tribal Community Family-Run Organization

- Family members go house to house explaining the purpose of the organization and inviting families to become involved with the group;
- FO-4 finds that some of the families are interested, others are not, but none has been negative.
- Understands the diversity within the tribal community (i.e., generational, socio-economic, etc.).

IPR: 3 FO-4 is reaching out to the diverse families within the tribal community. The organization receives some in-kind support to develop diverse leadership through the tribal council and the business community.

FO-5: County-wide Family-Run Organization

- The county has a large Latino population, about 38 percent, followed by a significant African American population, about 19 percent;
- Understands the need to engage diverse family leaders: in the state, there are more than 62 percent of children who are non-white.
- Only 1 – 2 family leaders from the organization are visible to the local system of care community.
- FO-5 is struggling to develop support from system of care entities to fully engage in recruiting and nurturing diverse family members from the community to build leadership.

IPR: 2 Although FO-5 is working to recruit diverse family members and expand their informal support network to build leadership capacity within their system of care, only one to two family leaders from FO-5 represent the organization's family voice. FO-5 receives no support in this area.

FO-6: County-wide Family-Run Organization

- Provides a number of opportunities for diverse family and youth to enhance their leadership skills;
- Family voice is represented at various levels of the system of care by a number of family members from FO-6;
- Other local service providers and child serving organizations encourage diverse family members to contact FO-6;
- State has funded FO-6 to build a working relationship with Native American organizations.

IPR: 5 FO-6 is supported contractually by arrangements with the state. Actively recruits, hires and trains racially, ethnically and other culturally diverse family leaders to interface with the system of care through the child and family serving workforce and in natural helping and volunteer capacities to develop family leaders.

Key Element 3

Family members operate in a peer support role to assist other families and youth.

STRATEGIES AND REALITY CHECK

FO-1: Statewide Family-Run Organization

- Operates in a peer support role and provides a variety of culturally and linguistically competent supports and services;
- All members of the organization are family members who have experience with the system because of their children's emotional or behavioral challenges;
- Youth employed by the organization have also had experiences with the system;
- FO-1 supports and services, based on family strengths, needs, culture and background, include the following: walk-in family center with clearinghouse of information and access to family staff; toll free helpline; English and Spanish website; a network of families supporting families by sharing experiences and strengths, and providing practical support and resources; education about families' and children's rights and how to advocate; knowledge of the education, child welfare, juvenile justice, and mental health systems; support for children's individual education plan and other strategic planning; assistance in accessing appropriate services, supports, and professionals for specific needs and assistance;
- A youth group for teens organized by teens to promote youth leadership and youth empowerment;
- Launching a Time Bank Network to support each other and support families of children and youth who are dealing with life's multi-stresses and mental health challenges that can compromise well-being and feeling connected to others in their community.

IPR: 4 FO-1 provides considerable peer support; however, FO-1 operates solely with grant funds to conduct peer support – it is not an institutionalized service within their system of care (i.e., is not reimbursed by Medicaid or incorporated into provider service contracts with state agencies).

FO-2: County-wide Family-Run Organization

- Operates in a family-to-family support role;
- Youth group began in 2004 to provide peer-to-peer youth support, educate community about stigma and challenges youth face, advocate for policy changes;
- FO-2 led community events to let families and the community know their voice is important;
- Develops networks and friendships and supports for families of youth who go into the hospital or are involved with the courts;
- Youth help each other to understand the community and family team process; the mental health, child welfare and juvenile justice system; their rights and how to advocate for their own needs.
- The state funds FO-2 to provide peer services and local care management entities are required to use FO-2 peer services.

IPR: 5 FO-2 is funded to provide family member and youth peer-to-peer support, which is an integral service and institutionalized through financial support within the system of care.

FO-3: County-wide Family-Run Organization

- Family members, many of whom arrived in the United States less than five years ago, depend on FO-3 to understand discrimination and their rights, provide information, referrals and system navigation;
- Some providers refer families to FO-3 for peer-to-peer support, to help build trust, generate hope, and help motivate other parents and family members to become involved in the system;
- As a grassroots, peer-to-peer support and referral group, FO-3 relies on parents and natural helpers in the community who have had experience navigating the system for their children;
- Conducts home visits with families to tell them about FO-3 and connect them with services for their children;
- Holds community events; hosts social activities, such as celebrating Hispanic heritage, birthdays, anniversaries, holidays, etc.;
- Peer to peer support is evident during the FO-3 meetings, where families bring their children to the meetings taking turns caring for the children during the meetings;
- A major challenge of FO-3 to helping family members operate in a peer support role is the language barrier. Many families are monolingual, speaking Spanish only, and often the peer support is monolingual, making it difficult to assist families with providers who do not have the language capacity to work with families whose primary language is Spanish.

IPR: 2 While some providers see FO-3 as providing peer-to-peer support, and while providing peer support helps FO-3 connect with families with similar cultures and language, the organization is not financially supported by the system of care to provide peer-to-peer support.

FO-4: Neighborhood-Based and Tribal Community Family-Run Organization

- Acknowledges that their strength is in the peer-to-peer support they provide. They see this approach as the way it has always been for them. Many of the daily activities of living, such as transportation to go grocery shopping or getting to town to take care of other business, depend on the good will and generosity of a neighbor;
- The new youth group is also exploring ways to reach out to other youth and provide peer-to-peer support to those who want and need it;
- Businesses within the tribal community have provided in-kind support.

IPR: 3 While peer-to-peer support activities are not supported institutionally or in any programmatic or systematic way, FO-4 operates in a culture in which they naturally provide and rely upon peer-to-peer support and many members of the community are extended family members.

FO-5: County-wide Family-Run Organization

- Provides crisis support to families and peer-to-peer support for families in school meetings and other child and family meetings with providers;
- With only one part-time paid staff person and increasing need, FO-5 is struggling to provide peer-to-peer support when requested.
- FO-5 is looking at ways to use natural helpers and volunteers more effectively.

IPR: 2 FO-5 provides the peer-to-peer support when it is able to within its limited capacity, but receives little to no support from the local system of care for this service to families or youth.

FO-6: County-wide Family-Run Organization

- Has worked with the state Medicaid office to create billing codes that support their peer-to-peer work. For example, parent partners provide specialized peer support to parents of children who are experiencing possible or current out-of-home placement;
- In addition to the tangible support and services provided by the parent partners, peer support addresses and validates feelings and concerns of families contemplating out-of-home placement or transitioning back into the home for their child by sharing parent partner's own experience with out-of-home placement.
- Staff within the organization are working through conflicting opinions about the level of direct service provision to families (i.e., some believe the organization should not be a Medicaid provider and a formal provider in the system, while others feel it is the only way to sustain itself and ensure quality, family-driven services).

IPR: 5 As a newly created category under Medicaid, peer-to-peer support is a covered service. FO-6 is a Medicaid provider organization and provides a variety of peer support services. The state has required every provider organization to use peer support.

Key Element 4

A family-run organization plays a key role in ensuring families and youth have access to needed quality services.

STRATEGIES AND REALITY CHECK

FO-1: Statewide Family-Run Organization

- Provides evaluation and assessment of the state's system of care services to help ensure that families have the quality services that they need (e.g., conducts focus groups with families involved in services to assess satisfaction);
- Provides individual assistance and advocacy when requested by a family;
- Conducts family focus groups which led to the development of a statewide hotline for children in emotional crisis;
- Views itself as a strictly grassroots organization and has chosen not to provide direct, Medicaid billable services;
- Does not have the capacity to provide the direct service resources identified by several system partners;
- FO-1 is seen as a leader in coordinating and providing necessary training to families, youth and service providers to help families access quality services across systems, however, FO-1 does not participate in most individual service and support planning meetings by its own choosing;
- Sees itself continuing to evolve, moving from attending all child and family team meetings to providing more training to empower the families themselves and mobilize a network of families.

IPR: 4 Although system of care partners would like FO-1 to become more involved at a direct service level, such as providing peer support, respite services, and support to families in wraparound meetings, the organization chooses not to focus on being a direct service provider, but rather working with family members to be their own advocates. FO-1 provides training to families in system characteristics and plays an active role in evaluating the delivery system and advocating for quality care.

FO-2: County-wide Family-Run Organization

- Working to inform families about what formal and informal services exist for their children;
- Emphasizes natural, community supports in child and family team meetings;
- Conducts joint training and coaching activities with care management organization and provides training to the care management organization and other providers in family-driven services;
- Families from FO-2 are members of a quality assurance committee charged with monitoring services provided to children, youth and their families. These activities are supported and encouraged by the state, as they are part of the deliverables that have been set by the state system of care initiative, and are expectations from the statewide coalition of family organizations.

IPR: 5 FO-2 is financially supported by the state to recruit, hire and train family partners who attend child and family team meetings, IEP meetings, court hearings and other meetings as necessary to assist families in accessing needed services and supports. The state also supports FO-2 to participate in quality improvement activities.

FO-3: County-wide Family-Run Organization

- Main activity is helping families to access services and supports that meet their needs, especially in light of the need for cultural and linguistic competence from the providers;
- Encouraged by the local system of care in this role, but there is no financial support for the work.

IPR: 1 The ability of FO-3 to help families access services and supports is limited, as the organization is not staffed. The services provided by FO-3 are not financially supported by the local system of care.

FO-4: Neighborhood-Based and Tribal Community Family-Run Organization

- Developing a network of families, many of whom have had experience with the services and supports that are needed by other family members;
- At this early stage of their development, concentrating on immediate concerns that impact the whole community. For example, the need to clean up the playground and make it a safe and enjoyable place for their children is a priority and example of providing quality care and support;
- Exist in a culture and community that does not bring negative attention to services and supports, but rather is looking at ways to improve and “build services up.”

IPR: 2 Some of the services and activities provided by FO-4 to help families access services and supports are supported through in-kind donations. The organization relies primarily on resources (i.e., people power, food, meeting space) provided by the family members.

FO-5: County-wide Family-Run Organization

- Works in a peer-to-peer approach to help families to access quality services;
- Director has very well established relationships with the provider community, which has helped direct families to appropriate services and support for their children and youth;
- The support, encouragement, and directive for this activity comes from the state’s Federation of Families.

IPR: 2 While FO-5 works directly with families in accessing services and supports, it operates as a one-two person operation, thus limiting its capacity to provide a large number of families with direct assistance and attend system of care meetings. There is little tangible support from system of care partners for this activity. Also, FO-5 is not supported to participate in quality assurance activities at state and local levels.

FO-6: County-wide Family-Run Organization

- Provides much of county’s services and supports to families;
- Provides referral to and system navigation of the county’s services and supports;
- Is supported by the state and county BHO to be involved in quality improvement processes to improve the quality of services.

IPR: 5 FO-6 is supported financially and philosophically by the system of care to be a major provider of and referral agent to services in the system of care. Mechanisms (i.e., Medicaid, leadership, strategic training plans) are in place to build the capacity of the organization to assist large numbers of families in need of services and supports. FO-6 also is supported by the state and local behavioral health managed care organization to participate in quality improvement processes.

Key Element 5

Family-run organizations play a role in changing the traditional relationships between families and government agencies, providers and advocacy organizations.

FO-1: Statewide Family-Run Organization

- Has been a core component of all the state's system of care planning and implementation;
- Although the state department of children, youth and families has been one of the strongest supporters of the development of the system of care in the State, support for the family movement has waxed and waned over the years, as evident from inconsistent amount of funding and reliance on funding of the organization from external federal sources, such as the CMHS system of care grants;
- Have been changes throughout the years on how "open" the major child serving systems have been to FO-1 involvement;
- Several family organizations in the state collaborate with FO-1 to help provide the necessary services and supports for the state's children, youth and families. One of these organizations is often considered FO-1's sister organization. FO-1 and this family organization have a memorandum of understanding which helps guide the collaboration. For example, the other family organization pursues the Statewide Family Network grant and FO-1 does not apply for funds from sources sought by the other family organization, such as educational grants;
- State increasingly recognizes that the value of family partnership can only be realized if family voice is instilled throughout all operations of a system of care.

IPR: 4 Although FO-1 must continually work to improve relationships with system of care partners (i.e., child welfare, juvenile justice, mental health, education, and health), their relationship with their partners over the last ten years has seen consistent improvement.

FO-2: County-wide Family-Run Organization

- Part of a statewide implementation of system of care;
- Has seen a number of changes in state government leadership and with each, an uncertainty of continued system of care support;
- Working on developing and strengthening relationships and partnerships with child welfare and the schools;
- Has strong relationship with local care management organization and with behavioral health across the board;
- Has very strong and productive relationship with the juvenile court;
- Conducts presentations to judges and their staff on system of care and child and family services;
- The family court makes referrals to the care management organization, who then contacts FO-2. Once a youth from the juvenile court is assigned to FO-2, FO-2 is involved with all court proceedings and assists the family in achieving its goals. The courts are made very accessible to FO-2 with an open door policy. With the family leading the process, FO-2 helps families provide the courts with prior court history and other pertinent information;
- Has developed effective and productive partnerships with community resources. For example, wrote a grant to partner with a local music studio to provide violin lessons to the children whose families are being served by FO-2;
- Has productive working relationships with a number of faith-based organizations, local libraries, and the Urban League.

IPR: 4 Partnership between FO-2 with the state and other state system of care-initiated family organizations was described as strong (although not to be taken for granted). FO-2 has strong working relationships with some child and family service entities (e.g., juvenile justice and community resources) and the care management organization, but is still working to develop strong relationships with other child serving entities (e.g., child welfare and education).

FO-3: County-wide Family-Run Organization

- FO-3 has strong ties with a service organization for Hispanic families, which refers families to FO-3, but the service organization provides no direct funding;
- One provider will soon have a grant to hire parent advocates and hopes the FO-3 can provide some parents, however, they must be fully bilingual in order to be advocates;
- Struggling to be a partner in the local system of care;
- Working on defining roles and relationship with other local family organization.

IPR: 1 Struggling to exist, FO-3 does not play a role in changing traditional relationships with government agencies, providers and advocacy organizations.

FO-4: Neighborhood-Based and Tribal Community Family-Run Organization

- Developed productive partnerships aimed at improving the lives of the children, youth and families in their neighborhood in the first eight months of their coming together.
- Forming a tenant volunteer program, FO-4 keeps a daily log of individuals who cut the grass in the neighborhood, and they in turn get a break on the rent from the housing department.
- Partnered with the Tribal Council to do a community clean-up, with the Tribal Council providing lawn mowers, rakes, and garbage bags and FO-4 providing the people-power.

IPR: 3 FO-4 is planning more community activities and successes so that local service provider tribal entities and advocacy organizations, state, and national organizations can be more aware of their existence, their purpose and their potential. As a family organization, FO-4 has a unique relationship with their government, the Tribal Council, and in working within these traditional relationships.

FO-5: County-wide Family-Run Organization

- Strength of relationships between the local providers and advocacy organizations and FO-5 is varied;
 - Struggling in its partnerships with local providers;
 - There is a level of tension that has not been adequately addressed, with a low level of trust between families and providers. It is the family organization that keeps the families at the table with providers;
 - Some system of care providers see families in a traditional sense, as recipients of service only.
- However, there are some providers who have expressed appreciation for the role of families and the family organization, indicating that they anticipate higher rates of positive outcomes when families are involved.
- System of care providers and community partners do not have a good understanding of how FO-5 operates on a day-to-day basis, and some partners would like to learn more about the services offered by FO-5 and how FO-5 is sustained.

IPR: 2 While some local providers understand that involving families at all levels and partnering with FO-5 is a fundamental component of system of care, this concept has not generally been implemented at the local level.

FO-6: County-wide Family-Run Organization

- Works with state, county and local child serving agencies to develop and implement policies, practices and community supports that build on the strengths of families and focus on family participation and support in a system of care.

IPR: 4 FO-6, in collaboration with other family and advocacy organizations, has played a major role in changing many of the traditional relationships with government agencies and providers. While FO-6 is a partner locally and in the state-wide system of care initiative, additional efforts are needed to fully partner between family leaders and provider management.

Key Element 6

Families are engaged in changing policy.

STRATEGIES AND REALITY CHECK

FO-1: Statewide Family-Run Organization

- Director is the representative of a statewide children's coalition of providers, families, and family organizations for a legislative budget hearing where the state children's budget and redesign of system of care is to be reviewed with key policy and proposed legislative items on the agenda;
- Distributes legislative briefs to family members and groups statewide as a call to action and in preparation for senate budget hearings;
- Contributes to the family-driven language in the state policy documents, such as the children's emergency services standards;
- Is usually encouraged and supported by system of care partners to engage families in changing the policies that impact their children and families.

IPR: 5 System of care partners encourage and support FO-1 efforts to fully engage families at various levels in changing policies that impact children, youth and families, including direct advocacy at state policy meetings and providing information and opportunities for families to engage in the policy change process. There is an expectation from the system of care that FO-1 will not only be involved in any policy change processes, but may be a leader in these efforts.

FO-2: County-wide Family-Run Organization

- Encouraged and expected through the state system of care initiative to provide parents the opportunity to learn about the legislative and budgeting process;
- State invites families to engage in policy discussions and provides the support to FO-2 that encourages families to be active participants in the legislative process;
- Parents testify before legislators, write letters, and educate legislators to the reasons families support certain budgets;
- Families are feeling empowered and excited to be a part of the legislative process to help direct and change the policies that affect their families.

IPR: 5 Even as a county-wide network, FO-2 is fully engaged in state policy change initiatives and processes. Family members are encouraged by the local provider community and state system of care to have their voices heard and lead change efforts that impact their children and families.

FO-3: County-wide Family-Run Organization

- Struggling to be supported to help engage Latino families in opportunities to change and affect policies about their children and families;
- While encouraged to do so, most respondents feel that the Latino voice is not supported and therefore not often represented at the state or county level where policy decisions are made, mainly due to the challenges presented by language and cultural barriers;
- Has been invited and funded through various federally funded organizations and national family organizations to attend meetings and conferences at the national level, where policy and future directions of mental health services are discussed (e.g., involved with the Migration Coalition dealing with immigration issues).

IPR: 1 Although FO-3 has had some involvement at the national level, as an organization, they are struggling to have their organizational family voice heard in the local system of care and in state policy processes.

FO-4: Neighborhood-Based and Tribal Community Family-Run Organization

- Working to establish itself as a viable and credible organization;
- Members of FO-4 are increasingly being invited to tribal government meetings and community gatherings to represent the family voice.

IPR: 2 FO-4 is being invited to the policy table; however, affecting policies is a challenging issue, as the family members of FO-4 are navigating cultural traditions and are respectful of the tribal authority and the wisdom of the elders in setting policies that impact their children and their families.

FO-5: County-wide Family-Run Organization

- Have a voice in the policy arena at the state level through their affiliation with the state Federation of Families for Children’s Mental Health;
- Supported and encouraged to provide training and advocacy to help families engage in the legislative process through the state Federation of Families.

IPR: 2 FO-5 has little influence over county policies and continues to work on increasing local support for their role in engaging families in changing policies that impact their children and families.

FO-6: County-wide Family-Run Organization

- Well-respected partner at the table of policy-makers in the community and at the state level;
- When government leadership and direction changes occur at the state level, the organization feels vulnerable.

IPR: 5 Although changes in state leadership and policy create a level of uncertainty for FO-6, the family voice, through FO-6 and other family organizations, is invited, encouraged and supported to help engage families in changing policies that impact families and their children.

Summary Ratings

The following table shows summary Implementation Partnership Ratings (IPR) for each organization in the study sample. To reiterate, this is not a rating of the family-run organization itself. It is a way to begin to measure the strength of the relationships between family-run organizations and their system partners. While there is certainly an element of subjectivity in the IPR, family-run organizations and their system partners might find it helpful as a tool to explore areas where because relationships are strong, the family-organization can be effective, as well as areas where relationships are weak and may be compromising the family-run organization's ability to be effective. The tool can point to areas where relationships need work. It can be used as a self-assessment tool over time to ensure that strong relationships remain so and those needing work receive appropriate attention.

Element	FO-1	FO-2	FO-3	FO-4	FO-5	FO-6
1. Targeted resources are in place to support the family organization	4	4	1	2	2	5
2. Culturally diverse family leaders are integral to the system of care workforce	5	4	2	3	2	5
3. Families operate in peer-to-peer roles	4	5	2	3	2	5
4. Families have access to needed quality services	4	5	1	1	2	5
5. Traditional relationship between family-run organizations and system partners are changed	4	4	1	3	2	4
6. Families are engaged in changing policies	5	5	1	2	2	5
Average IPR	4.3	4.5	1.3	2.3	2	5

Summary Observations

This monograph, based on the study, explores the relationships between family-run organizations and non-family-run partner organizations in systems of care and examines the relationships across six key elements essential to strong family voice and family-driven care. Study findings suggest the following:

- The stronger the relationship between the family-run organization and the non-family-run entities, the more likely that key elements essential to strong family voice are realized.
- A strong family-run organization is necessary, though not sufficient, to have a strong and sustained family voice in system of care. Non-family-run entities must commit themselves to operationalizing family voice through funding for family organizations, hiring family members as staff, including family partnership in policies, and the like.
- The relationship between family-run organizations and non-family-run entities in systems of care is developmental. Non-family-run entities typically exist before the development of family-run organizations. Family organizations often are launched at the start of system of care reforms. However, regardless of how long either entity has been in existence, the relationship between family-run organizations and non-family-run entities begins in “an infancy stage” and develops and matures over time. The relationship also is subject to “stops and starts” as leadership changes in both types of organizations (i.e., family-run and non-family-run system partner organizations). This is one reason why the age of a family organization does not necessarily equate to a strong relationship.
- The relationship between family-run organizations and non-family-run organizations in systems of care is complex in nature, and the strongest relationships appear to be those that are multi-textured. For example, in systems of care with strong family voice, the non-family-run entities consult with the family-run organization as a partner; support the family-run organization, not only with money, but with training and advocacy to carry out their responsibilities; use the family-run organization to trouble-shoot when they run into problems; are open to learning from them and vice-a-versa –operating as a learning community; and, pay attention to how much the family-run organization can handle in its development.
- There are times that an existing family-run organization does not meet the needs of all families. When this happens, the family-run organization, in partnership with other system of care partners, needs to put mechanisms in place so that all families’ needs can be met. Where there is more than one family-run organization in a community or state (or nationally), they must work together to achieve their mutual goals. For example, some family-run organizations reported that it can be difficult for each to have the same strength of relationship with non-family-run entities, and with each other. Missions, roles and responsibilities need to be clarified. The more unified the family organizations can be, the greater the opportunity for strong relationships across all entities.
- A challenge faced in providing culturally and linguistically competent peer-to-peer support is in family-run organizations that are working with primarily mono-lingual families, with mono-lingual peers, in a system operating primarily in a language other than that of the families and peer and workers.

- Family voice is most evident in systems of care when there is a strong relationship between non-family run entities and the family-run organization to support family voice at all levels, including: setting policies, developing programs, delivering services, and assessing the impact of the system of care.
- Family voice is supported when families serve in a variety of capacities within all operations of a system of care. A paradigm shift is needed from viewing families as recipients of services only to providers of information, services and supports for their own families as well as other families. In addition, many families view the provider array more broadly than just the traditional service providers from the public entities (i.e., mental health child welfare, education, juvenile justice, health) and include partnerships with faith-based organizations, businesses and recreational entities.
- In systems of care where families are receiving peer-to-peer support, the support may be operationalized differently across family organizations and within systems, but the common factor is that the support is family-to-family. Family-run organizations must be supported financially and philosophically by non-family run entities to provide peer support strategies. For smaller, newly developing family-run organizations with little or no funding, the central focus is peer-to-peer support on a small scale.
- There are levels and specific types of support necessary for the system of care to provide for families to successfully develop and sustain their own family-run organizations, including financial support, training, leadership opportunities, and the like. The level of support cannot be tokenistic.
- Peer-to-peer support from other family-run organizations (e.g., from the National Federation of Families for Children's Mental Health, other local family-run organizations, state-run family-run organizations, etc.) appears to be an essential component for sustaining family and youth work.
- When there is only one source of funding, it may be difficult to sustain the organization over time. This is obviously true with grant funding that typically is time limited. State legislated support/funding for family-run organizations, as well as a diversity of funding, can help to provide a level of certainty and stability.
- The importance of cultural and linguistic competence is reflected in the amount of resources provided by the system of care to operationalize cultural and linguistic competence (e.g., hiring and recruiting diverse family members, development and dissemination of linguistically competent materials, partnering with the family-run organization to hold community activities that reach diverse families, etc.)
- Where family-run organizations are helping to ensure the type and quality of care, there are policies and practices in place throughout the system of care that encourage and support family-driven monitoring and evaluation activities.
- Where family-run organizations are supported financially and philosophically by non-family-run entities, family-run organizations are helping families to access the system and to meet the needs and requests of families in their communities (e.g., legal advice about school suspension, medication questions, etc.). These family-run organizations are assisting families to have direct connections and access to mental health providers and other child serving agencies.

- While advocating for children’s services and supports, family-run organizations must also continuously advocate for their own sustainability and growth.
- A strong relationship between the non-family-run entities in systems of care and family-run organizations can lead to effective family voice in influencing legislative processes that have a bearing on children and families. The family-run organization must be seen as credible and viable to effectively advocate for policy change and participate in the policy arena.
- The National Federation of Families for Children’s Mental Health (FFCMH) or a state FFCMH organization can support and enhance the policy work of local family-run organizations. In turn, family-run organizations must be supported locally to engage in statewide and national policy work.
- State, local and system of care policy-making bodies must be culturally and linguistically competent for all families to have a voice at the policy table.

Understanding the strength and the nature of the relationship between family-run organizations and non-family-run entities in systems of care can be helpful in a number of ways, for example:

- How can federal reviews consider the relationship between existing family-run organizations and non-family-run entities as a factor in the development and growth of family voice?
- What do system of care grant proposals look like that address true sustainability for the family-run and youth-run organizations?
- How does the relationship between the family-run organization and the non-family-run entities impede or improve the system of care?
- How can the relationship be factored into the research on the development of family organizations?

The family-run organizations and their partnerships with non-family-run organizations do not develop in a linear way—they are much more dynamic and affected by environmental changes, such as political will, state, local and organizational leadership, and economic and social conditions. However, the strength of the relationship between the family-run organization and non-family-run partners in a system of care can help to secure the family organization’s developmental trajectory toward consistent growth as the engine of family voice and family-driven care.

Authors’ Note: Visit www.rtkids.fmhi.usf.edu for the upcoming study brief which will include the follow-up summaries for the 6 visited sites.

End Notes

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