

# Study 6: A Quick Guide for Self Assessment of Family-Run Organizations in Systems of Care: A Product of the National Survey Findings from Examining the Role of Family Organizations in Developing a Systems of Care Study

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# Study Purpose and Goals

- Examine how family voice, as represented by family-run organizations, contributes to the development, implementation and sustainability of local systems of care, and how systems of care contribute to the development and sustainability of family-run organizations. An embedded case study design is organized into five phases using survey research procedures and network analysis.

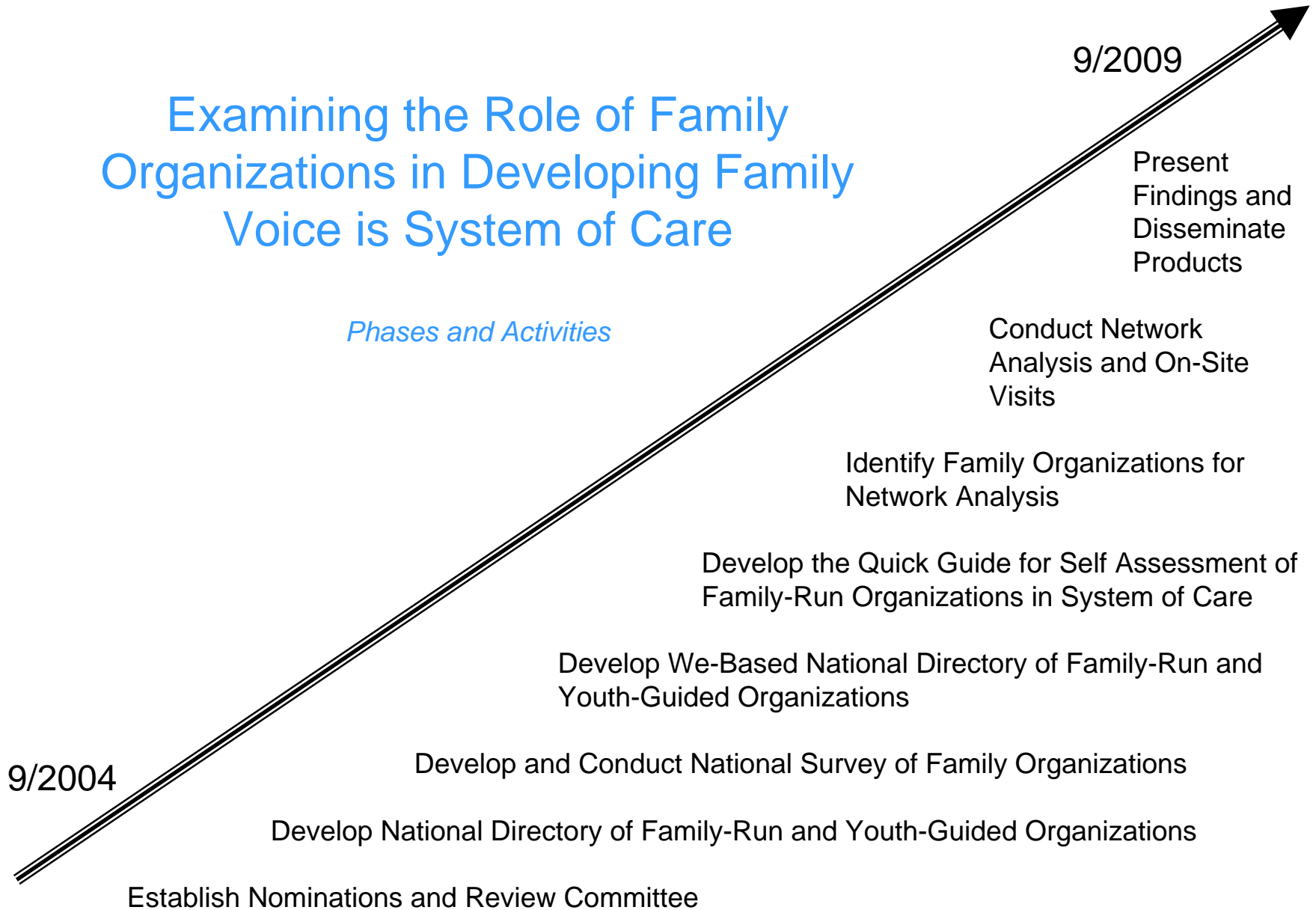


## Four research questions drive this study:

1. What factors support or impede the development and sustainability of the family organizations in the context of systems of care?
2. How do family organizations contribute to the implementation of local systems of care?
3. How do family organizations contribute to the sustainability of local systems of care?
4. How are the systems of care implementation factors understood and operationalized from the perspectives of family organizations?

# Examining the Role of Family Organizations in Developing Family Voice in System of Care

## *Phases and Activities*



# National Survey of Family-Run Organizations

## Preliminary Findings: Family Organization Characteristics (n= 20)

- Most started out as a grassroots organization or support group.
- Of those that are part of a CMHS System of Care community, most were in existence prior to the grant.
- Most are part of a local or statewide management team.
- Most of the referrals to the family organizations come from: 1) other families; 2) care managers; 3) judges; 4) teachers/ school counselors; and 5) community organizations.
- Most have multiple funding sources.



# Preliminary Findings: Importance, Effectiveness, and Extent of Support

Assumptions/Indicators	Importance	Effectiveness	Extent of Support
<b>6) The family-run organization has productive working relationships with state and local agencies, and providers.</b>	4.8	4.3	3.3
<b>4 &amp; 10) The family-run organization helps families have direct access to mental health providers and other child serving agencies.</b>	4.7	4.1	3.5
<b>7) Mechanisms are in place to sustain a family-run organization.</b>	5.0	3.0	2.6
<b>11) Youth are encouraged and supported to participate in all operations of the system of care.</b>	4.5	3.1	3.2

How important: 1= not at all important 2= minimally important 3=somewhat important 4=important 5=very important

How effective: 1=not at all effective 2= minimally effective 3= somewhat effective 4= effective 5= very effective

To what extent: 1= never 2= rarely 3= occasionally 4= frequently 5= always

# Anticipated Findings from the Family Organization Study

- Factors that contribute to the development and sustainability of family organizations.
- How family organizations contribute to the development and sustainability of systems of care.
- Typology of different structures of family organizations and their network relationships.
- Recommended methods that family organizations can use to help bring about system transformation.

# National Directory of Family-Run and Youth Guided Organizations for Children's Mental Health

<http://familyorgdirectory.fmhi.usf.edu/>

The directory lists family-run and youth-guided organizations and support groups throughout the United States, US Territories and Tribal Nations. You can search our database to find organizations across the country run by families or youth consumers that are working to support families who have children and adolescents with emotional/behavioral and or mental health challenges and to improve mental health services and supports.



***As of May 1, 2007 2,089 people visited the Directory, with a daily average of 34.***

# Family Organization Network Analysis

- National Survey of Family-Run Organizations mailing list helped to identify family organizations to participate in the network analysis phase of the study.
- Eight family organizations were identified.
- Each of the family organizations provided a mailing list of partners to be surveyed.
- Four of the eight family organizations and their communities have been visited and are engaging in network analysis activities.

***As one family organization director stated, “This activity, having to compile our contact list for the network analysis, has been really helpful to us. We are already benefiting from being part of the study.”***

# Quick Guide for Self- Assessment of Family-Run Organizations in Systems of Care

- Descriptions of nine important elements of family-run organization development and sustainability
- Self-assessment exercises



One family member stated, *“Congratulations on a well done, practical and useful handbook for family-run organizations.”*

***As of May 1, 2007, The Quick Guide has been downloaded 883 times since March 1.***

# Key Elements for Family-Run Organizations

- Values
- Leadership Development
- Partnerships
- Access & Referrals
- Meeting Family Needs
- Youth Involvement
- Working Relationships
- Sustainability & Growth
- Charting Progress



# Values

## Exercise 1: The Value of Family Partnership

*Complete Exercise 1 to begin examining the extent to which family partnership is valued throughout the system of care. Check if your organization is involved in the system of care activities.*

- The family organization is involved in setting policies in the system of care.
- The family organization is involved in developing programs in your system of care.
- The family organization is involved in training and technical assistance to enhance/expand family partnerships across system of care.
- The family organization is involved in assessing/evaluating the impact of the system of care on children, youth and families served, agencies and systems, and the community.

## Exercise 2: Local and State Leadership/ Management/Operations Teams

*Complete Exercise 2 to identify all the management or leadership positions of the system of care held by leaders from the family organization.*

- State/local governing body  
(e.g., \_\_\_\_\_)
- State/local advisory body  
(e.g., \_\_\_\_\_)
- State/local planning body  
(e.g., \_\_\_\_\_)
- State/local management team  
(e.g., \_\_\_\_\_)
- State/local quality improvement team  
(e.g., \_\_\_\_\_)
- Other state/local team  
(specify: \_\_\_\_\_)

# Leadership

## Exercise 3: Characteristics of Family Organization Staff

*Complete Exercise 3 to help you begin to look at leadership and workforce issues, including issues of cultural and linguistic competence. For each staff position you identify, indicate for the individual currently in that position, their gender, race/ethnicity, whether they reside in the geographic area served, whether they receive or have received services from the system, and strengths, skills, knowledge, they bring to that position.*

Position	Gender	Race/ Ethnicity	Reside In the Geographic Area Served	Other Cultural/ Linguistic Characteristics	Receives /Has Received Services from System	Strengths

# Partnerships

## Exercise 5: Family Involvement

Complete Exercise 5 to help you begin to identify where family involvement is “strong,” “needs improvement,” or is “non-existent” in your system of care. Examples of types of family involvement are included in each area, but add to the list as you think of other ways families can be involved in the system of care.

Activity	Involvement is Strong	Involvement Needs Improvement	Involvement is Non-Existent
<input type="checkbox"/> Setting child serving policies for your local system of care by...			
participating on governing boards			
participating on advisory boards			
participating on legislative liaison groups			
other:			
<input type="checkbox"/> Developing programs for your local system of care by...			
participating on service array committees			
participating on implementation committees			
participating on local management teams			
<input type="checkbox"/> Delivering services for your local system of care by...			
providing peer support role to assist other families in navigating systems			
providing families with information and emotional support			
parent-to-parent service providers integrated into service teams			
providing training and technical assistance			
other:			
<input type="checkbox"/> Assessing/evaluating the impact of services on children, youth and families served, agencies and systems, & the community by...			
collecting data			
interviewing			
designing surveys			
providing analysis			
disseminating findings			
other:			

# Access & Referrals

## Exercise 6: Ways to Ensure Access and Utilization

*Complete Exercise 6 to help you begin to look at issues of accessibility and identify ways your organization makes it easy for families and system of care partners to find you, contact you, and use your services and supports.*

- No fee or sliding scale fee for membership
- Provide stipends/gift cards
- Co-locate services (i.e., schools, food stamp office, etc.)
- Provide written information at other settings (i.e., pediatrician offices, schools)
- Utilize media (i.e., newspapers, television/radio ads, etc.)
- Develop outreach plans which include underserved families
- Build child and youth coalitions
- Partner with culturally diverse, grassroots community organizations
  
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

# Meeting Family Needs

## Exercise 8: Checklist of Roles and Responsibilities

*Complete Exercise 8 to identify activities of your family organization and help you begin to identify roles and responsibilities you may want to further explore.*

- mentoring
- information dissemination
- recruitment
- peer to peer support
- parent advocacy
- training for families
- organizing conferences
- evaluation
- direct contracted service (e.g., family navigator, respite)
- training for provider/system agencies
- attending conferences
- developing policy briefs
- social marketing
- attending system meetings
- strategic partnering
- consultation services
- input state legislation
- resolve conflicting perspectives on family inclusion
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



# Sustainability & Growth

## Exercise 10: Sources of Funding or In-Kind Contributions

*Exercise 10 lists examples of sources of funding and in-kind contributions to family-run organizations across the country. For each source, check if this is a funding source you have, you want to improve, or if you want to explore it further as a possible source of support. It may also be helpful to write in the amount of the financial contribution or the approximate dollar value of the in-kind contribution, and describe the in-kind contribution you are receiving or would like to explore further. Add other sources to the list that you may have or want to consider.*

Source	Have It	Improve It	Explore It	\$\$ Amount	Type of In-Kind Contribution
Federal					
Child welfare					
Mental health					
Juvenile justice					
Education					
Public health					
State					
Child welfare					
Mental health					
Juvenile justice					
Education					
Public health					
Local					
Child welfare					
Mental health					
Juvenile justice					
Education					
Public health					
Charitable contributions					
Membership dues					
Fundraising events					
Cooperatively agreements					
Medicaid					
Foundations					
Corporate giving					

# Youth Involvement

## Exercise 14: Youth Involvement

Complete Exercise 14 to help you begin to identify where youth involvement is “strong,” “needs improvement” or is “non-existent” in your system of care. Examples of types of youth involvement are included in each area, but add to the list as you think of other ways youth can be involved in the system of care.

Our family organization supports the development of a youth organization in the following activities			
	Involvement is Strong	Involvement Needs Improvement	Involvement is Non-Existent
<input type="checkbox"/> Setting child serving policies for your local system of care by:			
participating on governing boards			
participating on advisory boards			
<input type="checkbox"/> Developing programs for your local system of care by:			
participating on service array committees			
participating on implementation committees			
participating on local management teams			
<input type="checkbox"/> Delivering services for your local system of care by:			
peer support role to assist other families in navigating systems			
providing information and emotional support			
<input type="checkbox"/> Assessing/evaluating the impact of services on children, youth and families served, agencies and systems, & the community by:			
collecting data			
interviewing			
designing surveys			
providing analysis			
disseminating findings			

# Organizational Progress Chart

6 Months  
 12 Months  
 3 Years  
 5 Years  
 From \_\_\_\_/\_\_\_\_  
 to \_\_\_\_/\_\_\_\_

6 Months  
 12 Months  
 3 Years  
 5 Years  
 From \_\_\_\_/\_\_\_\_  
 to \_\_\_\_/\_\_\_\_

6 Months  
 12 Months  
 3 Years  
 5 Years  
 From \_\_\_\_/\_\_\_\_  
 to \_\_\_\_/\_\_\_\_

6 Months  
 12 Months  
 3 Years  
 5 Years  
 From \_\_\_\_/\_\_\_\_  
 to \_\_\_\_/\_\_\_\_

6 Months  
 12 Months  
 3 Years  
 5 Years  
 From \_\_\_\_/\_\_\_\_  
 to \_\_\_\_/\_\_\_\_

	Goals	Indicators	Strengths	Challenges	Person(s) Responsible
Working Partnerships					
Sustainability & Growth					
Youth Involvement					
Evaluation					
Legislative					

# Study 6: Plans for Coming Year

- Complete Phase 2 site visits and network analyses for all sites
- Provide family organizations an opportunity to self-nominate as participants in a sub-study examining the impact of the QUICK Guide for Self Assessment.
- Complete final report and article reporting the results of the National Survey of Family-Run Organizations.
- Develop the second National Survey of Family-Run Organizations utilizing lessons learned and findings from the first National Survey
- Present QUICK Guide for Self-Assessment Workshops
- Collaborate with Study 1 examining the role of family voice and family organizations as system of care implementation factors
- Collaborate with Study 2 examining the strategies of family organizations in system of care implementation and the strategies of system of care partners in supporting family organizations
- Collaborate with Study 3 specifically examining financing structures for family organizations
- Collaborate with Study 5 examining the role family organizations play in reducing mental health disparities
- Disseminate findings

# For More Information on Study 6:

<http://familyorgdirectory.fmhi.usf.edu>

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