

What Do Family Organizations Do?—

A Comprehensive Study of Family Organization Practices

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3/23/2005

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Introductions

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Florida Institute for Family Involvement
- Shelley Spear
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Objectives

- What are Statewide Family Networks?
- Why research the practices of SWFNs?
- What can be done with the research?
- What form should the research take?

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It Seemed Like a Good Idea

- Family Partnership improves ownership
- Community based care is more accessible
- Culturally competent care is more effective
- Families are natural advocates and leaders



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Family Partnership makes Good Sense

- Families know their child completely.
- Families have the sense of urgency to improve system/child.
- Parent reports of symptoms are critical to care and affect placement options.
- Families are often the one constant in a child's life of multiple transitions.
- Family ownership is essential to effective care planning and implementation.
- Families assist in outreach, networking and organizing.
- Their experiences with the system, both good and bad, can positively impact service delivery planning and reform efforts.

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Change=Opportunity

- Easier said than done
- Practice wasn't standardized
- Practice wasn't valued as professional
- Practice wasn't recognized as legitimate
- Practice was threatening to providers
- Practice was outside the scope of work
- Partnership takes practice and patience

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No Family Partnership Models

- Nationwide and Statewide, Family Partnership programs or organizations had to make it up along the way
- Nationwide and Statewide, System of Care sites interpreted, translated and implemented family partnership
- Insufficient family network support, infrastructure, planning, and evaluation

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SAMHSA Grant for Statewide Family Network Technical Assistance Center

- New money = serious intention and competition
- The new kid on the “grant block”
- The little family-run organization that could...
- The need to validate and evaluate all the hard work of the Statewide Family Networks and family partnership

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Statewide Family Networks

- SAMHSA currently funds 43 statewide family-run organizations
- Activities implemented by these 43 family organizations have been documented by data reported under the Government Performance and Results Act (GPRA)
- Each activity represents a different means toward the common end – improved outcomes for children and families
- Each activity presumably creates its own ripple effect toward systems change

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Florida Institute for Family Involvement

Who we are...

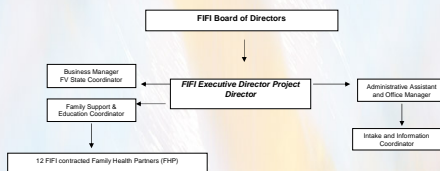
A non-profit family run organization with a 501C3 status for the purpose of enhancing, facilitating, and supporting family and consumer involvement in the development of responsive, family centered, and community based systems of care.

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Organizational Structure



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What we do...

- Strengthen partnerships
- Foster family centered systems of care
- Create leaders
- Share information

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Who we represent...

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

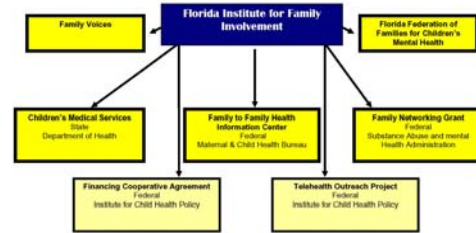
(Maternal and Child Health Bureau – MCHB)

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Projects



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Activities

Children's Medical Services

- Family Health Partner Program
- Quality Improvement State Monitoring Team
- Special Additions
- Grievance Committee
- Critical Partners Conference

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More...

- **Family to Family Health Information Center - CSHCN**
 - Data Collection
 - Information and referral
 - Enhancing Family Capacity
 - Leadership development
 - Training
 - Systems Change
 - improved access
 - medical home
 - screening
 - transition
 - family involvement
 - coordination

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More...

- **Family Networking Grant – mental health**
 - Leadership development
 - Systems change
 - Organizational networking
 - Data collection
 - Family information and support resources
 - Youth development

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And even more...

- National Financing grant
- Statewide insurance/telehealth grant
- Association of Maternal and Child Health Programs
- Community Based Care
- Emergency Medical Services for Children-State and National
- Informed Consent and confidentiality - DCF
- Family CAFÉ

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Whew...

- Family Voices
- FL Federation of Families for Children's Mental Health
- Statewide Cultural Competence Collaborative
- Family Viewpoints Survey
- Care Coordination Survey
- Navigator Revision

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The Numbers

	Total 6/04-1/05
Requests for assistance by telephone, email and in person: initial and follow-up calls,	60,451
Meetings/presentations/conferences Topics presented: Health Care Financing, Health Care Policy, Disability Specific, Education, Screening, Medical Home, Mental Health, Oral Health, Parent to Parent, Respite, Transition, Parent Leadership, Collaborating/Partnering, Data Collection	122 presentations 37,774 attendees
Information/materials disseminated by mail or in person,	52,774
Number of newsletters and articles in newsletters disseminated,	69,000
Number of website hits,	208,829
Numbers reached by List serves	969

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Evaluation & Reporting

- 62 deliverables for DOH contract
- Quarterly data reporting for F2F Grant
- Annual GPRA Report for SAMHSA Grant
- Annual reports and re-applications for two federal grants
- Quarterly Trend Reports for state partners
- Annual Administrative Monitoring
- State audits

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How Family Organizations Differ

- Hard to define services provided
- Family centeredness is not easy to measure
- Outcomes are often based upon subjective opinion
- Data collection capacity is minimal
- Evaluations are seldom based upon a family organization "norm"

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Differences, continued

- Family organizational reporting and collection of data is driven by multiple systems
- Family organizations seldom fit "form" approaches to evaluation of effectiveness and outcomes
- Documentation of family intervention efforts is not scientifically based
- What makes the organization unique and different from professional driven business is what forces evaluation adjustments

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Organizational Considerations

Things we had to consider:

- What is expected
- How much staff time will it take
- How does it fit within the mission
- Could funding be jeopardized
- How will we look
- How to separate accomplishments to ensure appropriate credit to variable funding sources
- How to accurately describe activities
- How to link activities to outcomes

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The Research Project

- Conceptualization and planning
- Staff developed an outline
- Purpose and audience defined

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Family Organization Practices

- Activities of the forty-two (at that time) Statewide Family Networks
- Ideal outcomes the Networks are working toward.

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Purpose

1. Peer-to-peer knowledge exchange
2. Marketing/public relations
 - a. Larger community
 - b. Networks better understand their own programs
 - c. Contribute to the legitimacy of family partnership programs
3. Delineate a national framework/model
4. Create model for structuring evidence-based FO practices

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Audience

- Networks
- Grant Officers
 - Other TA Centers
 - Center for Mental Health Services
 - Other federal child-serving agencies
 - State and county child-serving agencies
 - National professional associations (Social Work, Psychology, Psychiatry)

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Overview of the Publication

- Background/Introduction
- Representation of Activities
- Practice to Science
- Science to Practice
- Theory of change
- History of the family movement

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Timeline

- Setting up and reviewing the interview process
- Contacting appropriate subjects and scheduling the forty-two interviews
- Conducting the audio-taped interviews
- Transcribing the interviews
- Creating process to categorize transcribed interview data
- Creating a database to collect and organize interview data
- Inputting data into the database
- Examining cross-rater reliability
- Compiling data
- Writing/Reviewing/Editing
- Producing/Printing/Distributing

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Interview Process

- Installed recording device
- Transcriber was contracted
- Pair of practice interviews were completed
- TA Center staff had a conference call to discuss the process and refine interview techniques

- A contact log was kept

(The contact log showed that the average number of contacts necessary to schedule interviews with each Network was 6, including telephone conversations/messages and email messages. Of the 42 Networks, 33 required rescheduling of interviews; 9 were rescheduled twice, and 5 were rescheduled 3 or more times.)

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Interview Process

Opening Statement to Interview Subject:

Family Partnership Organization Practices is being created by the Statewide Family Networks Technical Assistance Center for the purpose of providing Networks and others with a comprehensive description of the aims and activities that characterize the various organizations. The publication will facilitate knowledge exchange between Networks and will assist in public relations efforts. It will also help to generate an evidence-based framework for family organization programs.

Interview Questions:

- What are the activities your organization engages in? What else?
- What are the desired outcomes of these activities in relation to their impact on children and families?
- Follow-up questions: based entirely on content of above answers

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Processing Transcripts: Analysis of Activities

- Staff meeting to discuss the processing of the first section of the transcripts, which generally focus on family partnership organization activities.
- Activities would be isolated within the transcripts by three staff members, each taking one-third of the transcripts.
- List of activities would be inputted into a database that contained the following parameters:

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Data Input

1. State
2. Point of Impact
3. Practice
4. Activity

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Points of Impact

1. Community
2. Service delivery system
3. Child and family
4. Public policy

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PRACTICES

1. Care management/planning
2. Community presentations
3. Efforts to inform legislators
4. Emotional support
5. Participation in administrative meetings
6. Participation on policy committees
7. Produce art
8. Publish and disseminate information
9. Referral
10. Training

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Activity

Description of the exact action of the Network

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Meanwhile: Individual Network Reports

Secondary Project Goal:

- Provide each of the Networks with a product that outlined its individual activities and outcomes.
- The reports are intended for use by the Networks for marketing and public relations purposes, financial sustainability efforts, evaluation, and other purposes.
- Forty-two Individual Network Reports were drafted and disseminated to each of the Networks. (These documents were considered confidential and were not distributed beyond the individual Networks they described.)

Following the inputting of data, a staff meeting was held to discuss next steps. At this meeting, and during subsequent meetings, it was determined that the above process did not suit the original purposes of the research, which was to allow the data itself to determine the method of categorization. In other words, while we had intended to use an inductive process of data analysis, we were using a process that was overly deductive.

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Midcourse Correction

- **Staff determined a new course of action for analysis**
- **Three staff members read all forty-two transcripts**
- **Activities were isolated, but in original language**
- **Lead data analyst combined all lists**
- **Final list of activities compiled by the lead data analyst**

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Protocol for Making Lists of Activities

Protocol for Making Lists of Activities

1. Read the transcripts.
2. As you read, using the following definition of "activity," highlight each discrete activity:
Activity=any action sponsored by a Network
3. Form lists for each Network.
4. When lists are finished they are compiled, and one complete list is created

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Where We Are Now

- We have categorized all 1350 activities according to one or more of 29 rough categories
- Categories will be combined and refined
- Categories will be defined
- Numbers will be analyzed and charted (for example, how many Networks have youth group meetings?)

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Conclusion

- Where should we go from here?
 - Alternate forms of research of FO practices?
 - More research to link specific outcomes to each of the activities/practices?
 - What else?

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