



MODELS OF FAMILY-RUN ORGANIZATIONS

In the 1980's, pioneers in the children's mental health movement recognized the absence of family voice in the newly developing system of care for children. They also realized the critical value and unique role that families who have navigated the system for their own children could provide to other families entering the system. Family-run organizations became the vehicle to sustain the ongoing voices of families across decades. As family-run organizations have developed across the country, they took on very different structures. This paper will discuss the different models of family-run organizations, while also highlighting the common threads that bind them together.

What Are the Origins of Family-Run Organizations?

Family-run organizations began to develop in 1980's as a result of federal funding for states to receive Child and Adolescent Service System (CASSP) grants. For the first time, these grants required "family input into the planning and development of service systems, treatment options and individual service options."

The success of CASSP, prompted SAMHSA to create what is known as the Comprehensive Community Mental Health Services for Children and Their Families Program, most commonly referred to as Systems of Care grants. These grants were first awarded in 1993 and required family involvement as an integral component of the system.

Throughout this time, the family movement had begun to take on a life of its own with families across the country coming together to support each other and to change policy, programs and funding for children's mental health services. In 1989 the National Federation of Families was started by 16 families who believed that the voices of families needed to have a unified voice and national platform.

SAMHSA began funding nine Statewide Family Networks (SFNs) in 1985 and by 2006, the number of Statewide Family Network grants grew to 45. However, by 2014, the number decreased to 35 SFN grants. Presently, there are approximately 200 local or state family-run organizations dedicated to children's mental health.

What Are Family-Run Organizations?

The foundation of a family-run organization consists of four essential elements:

- **Mission:** Dedicated to supporting families caring for a child or youth with mental, emotional, behavioral or substance abuse needs
- **Governance:** Board of the organization is comprised of at least 50% family members with "lived experience"
- **Personnel:** Executive Director and all staff members providing support are family members
- **Family voice:** Promotes family voice at all levels of the organization and system

Families with "lived experience" are defined as parents, relatives, or foster families who are or have been the primary caregiver for a child with mental health, emotional, behavioral or substance abuse needs.

What Do Family-Run Organizations Do?

Family-run organizations may offer a range of services including:

- Develop an information and communications network
- Provide peer-to-peer support for families
- Facilitate support groups
- Provide training for families and professionals
- Hold conferences
- Publish newsletters
- Conduct public awareness and information campaigns
- Create and connect families to informal supports
- Advocate for families
- Advocate for systems change within multiple systems including: Juvenile Justice, Child Welfare, Substance Abuse and Education/Special Education
- Partner with multiple stakeholders
- Support and develop youth leadership
- Collect data and evaluate
- Serve as cultural brokers and language interpreters
- Conduct and participate in research

What Factors Influence the Structure of a Family-Run Organization?

Each family organization is different and is a reflection of the community or state they serve. They offer different programs and are structured very differently. The structure of the organization is often a result of a combination of factors:

- **State/region/ community's history and geography:** A large rural state may have to organize very differently than a smaller more densely populated state.
- **Stage of organizational development:** Like many non-profit organizations, family organizations evolve over time and the structure may change as the organization grows and matures.
- **External environment:** Factors, such as legislation or law suits, often play a role in shaping the structure of a family organization.
- **Internal decisions:** The organization's leadership, including the Board and Executive Director, may determine or alter the structure of the organization through Board decisions or a strategic planning process
- **Transitions:** Significant transitions, such as the start or end of a grant or changes in leadership, especially the founding leader, may abruptly change or influence the structure of the organization going forward.

Models of Family-Run Organizations

While each family-run organization is unique, there are four major state structures that have evolved over the last two decades. These are: Affiliate Model, Umbrella Model, Central Model and Advocacy Model. The following pages briefly describe each of these structures.

Umbrella Model

An umbrella family-run organization is an association or coalition of family-run organizations within a state, who work together formally to coordinate activities or pool resources. Often, the umbrella organization provides resources, services and sometimes an identity to the smaller organizations. In this kind of arrangement, the umbrella organization may, to some degree, be responsible for the groups under it. There may be many reasons for establishing/joining an umbrella organization:

- The ability to carry out activities which could not be accomplished alone
- A unified voice
- State presence
- Economies of scale
- An increased brand/public awareness
- Standardized services and training
- Standardized data collection and evaluation for outcomes
- A sense of community and support for families

In this model, each organization is an independent non-profit organization with their own Board of Directors and budget. Each organization hires their own staff. The umbrella organization is also an independent non-profit with its own Board. This Board may or may not include members of the smaller organizations on the Board. The umbrella organization may have contractual agreements with each of the smaller organizations and may be a conduit for funds from the state.

Nebraska Federation of Families is an example of an umbrella organization. In 2010, Nebraska created a Family Network and the Nebraska Federation of Families was appointed the Network Manager over six regional family organizations. All of the organizations have a shared vision, united voice, shared resources, standardized policies/procedures, training for Family Peer Support services and training, data management and program outcomes, and affiliate expectations. The Nebraska Department of Behavioral Health and Child and Family Services contract with the Nebraska Federation to do the network management and to subcontract for services with the regional family organizations. The Nebraska Federation has an independent Board of Directors.

Affiliate Model

An affiliate model is a family-run organization that develops affiliates or chapters of the organization throughout the state. The affiliates generally operate under the name of the parent organization. There may be criteria required, such as adopting the parent organizations' mission or agreeing to carry out certain activities in order for an entity to become an affiliate. Affiliates may be independent non-profits or may operate under the legal status of the parent organization.

The Federation of Families for Children's Mental Health ~ Colorado Chapter is an example of an affiliate model. The Colorado Federation has a central office that is the administrative hub. The role of the central office is to develop local affiliates throughout the state. The affiliates operate under the Federation of Families for Children's Mental Health ~ Colorado Chapter's name, corporation and non-profit status. In order to become an affiliate, the local group must complete an application and establish its own form of governance. To date, four affiliates have been established. Some affiliates have employees; some may operate with volunteers. The Colorado Federation administers all of the grants and funding for each of its affiliates and employs staff in the affiliates. One representative from each affiliate has a seat on the Federation of Families for Children's Mental Health ~ Colorado Chapter's Board of Directors.

Centralized Model

A centralized model is one family-run organization that concentrates all administrative and fiscal functions, as well as program functions. All staff members are employees of the one organization. There is cost effectiveness in centralizing all administrative functions, such as:

- Fiscal oversight, i.e. one payroll, one audit
- Economy for purchasing supplies and equipment
- Economy for purchasing and administering benefits for employees
- Unified family voice
- Statewide identity
- Statewide functions such as, advocacy, social marketing, training, and public education

The Maryland Coalition of Families for Children’s Mental Health (MCF) started as a loosely organized coalition of five small organizations. As a result of a strategic planning process, the MCF Board made a decision to move away from a coalition to becoming one centralized organization. All of the MCF staff members are employees of the organization and staff members are located in regions throughout the state. Some programs are centralized, such as legislative advocacy and public awareness, whereas, staff in each of the regions develop family support programs based on the need in their communities.

Advocacy Model

The advocacy model is one where the family-run organization focuses on systems advocacy and influencing policy as a means to improve the services and supports for individual families.

The Massachusetts Parent Professional Advocacy League (PPAL) is an advocacy organization. As a result of the federal Rosie D. lawsuit in Massachusetts, the state funded family support partners located in provider agencies. The PPAL Board made a decision to focus on becoming the training experts for family support partners and providing technical assistance to providers on family support and to focus on systems advocacy rather than becoming a provider.

Hybrid Models and Mergers

There is no model that is perfect for every state or local jurisdiction. The decision about the structure of a family-run organization must be determined by family leaders, taking into consideration the economic and political climate within their state, partnerships with state and community agencies, and the stage of organizational development. In an every changing economy and fast moving technology, mergers of family-run organizations, coalitions and hybrid models of family-run organizations are emerging. The hallmark of family-run organizations that have thrived over the decades is **flexibility**. Like our families, family-run organizations must be flexible and adapt to an ever changing environment.

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