



Models of Family-Run Organizations

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WHAT ARE FAMILY-RUN ORGANIZATIONS?

Family-run organizations (FROs) are family-led, 501 (C)(3) non-profit organizations dedicated to supporting families who are caring for children, youth, and young adults with social, emotional, substance use, or multi-systems challenges – and the agencies that serve them. They are governed and guided by the “lived experience” of families. Family-run organizations encompass the collective lived experience of families in their states and communities. They are specialty providers, each as unique as the families they serve.

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

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

“Lived experience” is defined as a parent or another individual who is, or has been, the primary caregiver for a child with mental health, emotional, behavioral, or substance abuse needs.

WHAT DO FAMILY-RUN ORGANIZATIONS DO?

FROs provide a variety of services and supports to help families navigate complex service systems, access necessary resources, and develop the knowledge and skills they need to improve their lives and the lives of their children. To ensure that services and supports meet the needs of youth and families, family-run organizations play a wide range of pivotal roles in preparing and supporting families to participate in the service, agency, and policy arenas. Examples include ensuring that families have the information they need to make decisions about their child’s care; providing peer support and navigation for families and youth; delivering training and workforce development for professionals across child-serving systems; participating in continuous quality improvement processes; engaging as partners in research; serving as members of care coordination teams, and informing public policy decisions. <https://www.fredla.org/areas-of-focus/family-run-organizations> .

FACTORS THAT 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, have access to various funding sources, 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 and the structure may change as the organization grows and matures.
- ✓ **External environment:** Factors, such as funding, public perceptions, legislation, or litigation, 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, four major state structures have evolved over the last few decades. These are the Affiliate Model, Umbrella Model, Central Model, and Advocacy Model. The following pages briefly describe each of these structures. Because the families in your area may have various needs, it can be confusing to decide what to offer and the infrastructure that will best support your choice. It is important to remember that you may choose a model now, but it could change in the future.

Umbrella Model

An umbrella family-run organization is an association or coalition of family-run organizations within a state, that 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 can 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 its own Board of Directors and budget. Each organization hires its 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 state, national, or federal sources. These connected organizations often have a shared vision, united voice, shared resources, standardized policies/procedures, trainings, data management, program outcomes, and affiliate expectations.

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 for an entity to become an affiliate, such as adopting the parent organization's mission or agreeing to carry out certain activities. Affiliates may be independent non-profits or may operate under the legal status of the parent organization.

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 decided to move away from a coalition to become one centralized organization. All of the MCF staff members are located in regions throughout the state and are employees of the organization. Some aspects of the programs are centralized, such as legislative advocacy and public awareness. Staff in each of the regions develop family support programs based on the needs of their communities.

Advocacy Model

The advocacy model focuses on systems advocacy and informing policy as a means to improve the services and supports for individual children, youth, and families. In this model, the family-run organization engages with a range of diverse families to understand their experiences with multiple child-serving systems and reflect the collective experience of families throughout the system change process. While other models may include this focus, it is the primary function of the advocacy model.

In 1991, the Massachusetts Parent Professional Advocacy League (PPAL) was founded as an advocacy organization. Because of the federal Rosie D. lawsuit in Massachusetts, the state-funded family support partners to be located in provider agencies. The PPAL Board decided for the agency to become the training experts for family support partners, providing technical assistance to providers on family support, and to focus on systems advocacy rather than becoming a provider. PPAL now employs families who have direct experience in raising youth with emotional, behavioral, and mental health challenges to support other families through providing support groups, building advocacy skills, sharing knowledge, and helping families connect with resources and services that work for them. They supply the information families need to understand and participate in the systems serving their children. In 2024, their focus is training, advocacy, family support, and youth support.

Hybrid Models and Mergers

No model is perfect for every state or local jurisdiction. Family leaders, taking into consideration the economic and political climate within their state, partnerships with state and community agencies, and their stage of organizational development, must determine the decision about the structure of a family-run organization. In an ever-changing economy, fast-moving technology, shifting political climate, and redesign of the mental health landscape, mergers of family-run organizations, coalitions, and hybrid models of family-run organizations are emerging. The hallmark of the family-run organizations that have thrived over the decades is **flexibility**. Like our families, family-run organizations must adapt to an ever-changing environment – not only seizing opportunities but also creating them.