

FROM THE GROUND

Family-Run Organizations (FROs)



A Program of Mental Health Transformation
Alliance (MHTA)

2023

EXECUTIVE SUMMARY

Research has shown that *authentic* family and youth participation, partnership, and leadership are the most effective factors in positive outcomes for children and youth. *Authentic* voices are those of families, youth, and/or young adults currently receiving or needing services. However, as systems, leadership and environments shift or change so does the level of knowledge and support around family engagement and partnerships with family-run organizations. Partnerships have become strained or non-existent, and funds previously specifically allocated for family-run organizations are being redirected. This is impacting decades of infrastructure development and relationship building between FROs and system of care partners on the local, state and national level.

Family-run organizations and family-driven movements built on authentic family voice and individuals with lived experience are facing extinction at a time when they are needed now more than ever.



ABOUT US

A FAMILY RUN ORGANIZATION (FRO) is a unique advocacy and support organization that is established and led by family members raising children and youth/young adults with behavioral health needs including serious emotional disturbance (SED). We support parents and caregivers of children, youth and young adults living with behavioral health needs and/or intellectual and developmental disabilities (I/DD). We also support individuals who have been unsheltered and/or part of cross system agencies such as: mental health, foster care/kinship care, child welfare, substance use, juvenile justice, education, public health or other systems thus creating a level of expertise called "lived experience". We often provide peer-to-peer support, meaningful connections, opportunities for education and training, advocacy, navigation and information/referral services to reduce isolation as parents and caregivers partner with providers to make informed decisions. We help families find and strengthen their voice at child, youth and family serving tables as well as facilitate the collaboration, process, and partnerships between families and communities.

"A GOOD SYSTEM SHORTENS THE ROAD TO THE GOAL" -
ORISON SWEET MARDEN

ROLES

Support and resources offered by each family-run organization are unique. However, no matter the population of focus, each FRO is a reflection of the cultures and families they serve within their community and/or state. FROs can be topic or disability-focused in education, mental health, or foster care while others are cross-systems and/or cross-disabilities missioned. The breadth of services FROs can:

Provide

- Information and referrals
- Hotline/helpline services
- Parent-peer support services
- Youth peer support services
- System navigation services
- Respite services
- Support groups for families and youth
- Peer support and resources as members of 988 suicide prevention efforts
- Education and training opportunities for families, youth, young adults and agencies
- Services for families and youth in partner with child-serving systems
- Social and recreational activities for families and youth
- Information for community outreach and social media outlets
- Advocacy and partnership development for behavioral health services and programs

Participate in

- Development of policies and processes
- Design and implementation of services and supports
- Development of financing for services and supports
- Evaluation of policies, services, and supports
- Research and data collection
- Recruitment, education, and support of family members and youth to participate at the system/policy level
- Development and delivery of strategic communications
- Hosting and participating in conferences for families and agencies
- Technical assistance, resources and support around family and youth-driven practices at all levels of processes and policies

Promote

- Family-driven and youth-driven practices at all levels of processes and policies
- Development of family and youth leaders to participate at the system/policy level
- Family/agency co-training efforts and partnerships
- Awareness, respect and acceptance around children's mental health and family-driven care
- Training and certification of parent peer support providers and youth peer support providers

STATISTICS

For example...



13 FROs reported that they **served 2,805 families** on average in their state yearly. *(Statewide Family Network Grantees, 2023)*



13 FROs reported that they **play a critical role** in child-serving systems at the local, state and national levels. *(Statewide Family Network Grantees, 2023)*



13 FROs reported that they **make up** a small proposition of the **1.5 million non-profits in the US**. *(Statewide Family Network Grantees, 2023)*



13 FROs reported that they **partnered with 75 providers, agencies and community-based organizations** on average yearly. *(Statewide Family Network Grantees, 2023)*



FRO's **advocate** for families, youth, and young adults involved with multiple systems to receive high quality, culturally responsive behavioral health care.



National Parent to Parent confirms that **family to family support increases resilience and skill building**. Parent to Parent's value is that "no parent should feel alone." *(Parent to Parent USA, 2023)*



When we look at the volumes of data and information available, there is only **ONE FACTOR** that consistently reappears in the research across agencies that serve children and youth: **family engagement is the most important factor in positive outcomes for children and youth and their families**. *(NC Collaborative for Children, Youth & Families, 2023)*



According to research conducted by the Beach Center, Kansas University, regardless of the age of their child with a disability, **two-thirds of the parents ranked having someone to listen and understand as a preferred emotional support**. *(Beach Center on Disability, 1996)*



60% of Parent Partner paired **families were reunited** within 12 months of removal as compared to **26%** families that **did not have a Parent Partner**. *(Casey Program, 2021)*



RESOURCES

[Models of Family-Run Organizations, FREDLA](#)

[Family-Run Organization Info Graphic, FREDLA](#)

[The Role of Family-Run Organizations in System of Care, FREDLA & National Association of State Mental Health Program Directors](#)

[Standards of Excellence for Family-Run Organizations, FREDLA](#)

NC Collaborative for Children, Youth and Families “Invest NOW: Family Movement In North Carolina” Resource
Paper *(in the process of being finalized for dissemination)*

[Research Highlights, Topic: Parent to Parent, Beach Center on Disability](#)

[Program Healthy Programs Casey Program](#)

[No Parent Should Feel Alone](#)



This document serves as an overview of the expertise, role, and impact of a Family Run Organization.

This is provided to you by Authentic Voices, a program of Mental Health Transformation Alliance (MHTA). We will be publishing a resource paper with detailed information related to this topic within the next few months.

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