Family Run Organizations: Nationwide Services and Supports Summary Report

A survey conducted by the National Federation of Families for Children’s Mental Health

July 2019
**Introduction:**

Family-run organizations (FRO) grew out of a dissatisfaction for service delivery systems and a fundamental belief that families are the experts regarding their children’s strengths and challenges. Supportive professionals played a huge role in the early years of the family movement and have remained steadfast in their support as these organizations have evolved to meet the needs of a rapidly changing environment. Currently, approximately 125 organizations and partners comprise the National Federation of Families for Children’s Mental Health (NFFCMH) nationwide network. These organizations range in size from large, statewide to local, grassroots groups, all of whom play a vital part in their communities.

As the needs of families and their children have evolved, so have the services and supports that are provided by FROs. Diagnostics have improved and have revealed that our children and young people are often more complexly diagnosed than once believed. The drug crises that our communities continue to battle have left their mark on our families and their children and have created a need for expansive supports. As these dynamics have emerged, NFFCMH conducted a survey of FROs to determine how this evolving landscape has affected their focus.

**Acknowledgements:**

NFFCMH greatly appreciates the family leaders who responded to the survey (listed on the following page). This survey was conducted without the use of any federal or state funds and does not reflect the views, opinions or policies of HHS, SAMHSA, or CMHS.

Adults Pushing Forward, Inc./Young Adults Pushing Forward
Idaho Federation of Families for Children’s Mental Health
Allegheny Family Network
Kentucky Partnership for Families and Children, Inc.
ASK Family Services
Keys for Networking
AspireHope NY, Inc.
Maryland Coalition of Families
Camden County Family Support Organization
MIKID (Mentally Ill Kids in Distress)
Champions for Children’s Mental Health
Mini Minds Matter
F.A.C.T.
NAMI New Hampshire
Families as Allies
North Carolina Families United
Families CARE
Nebraska Family Support Network
Families Inspiring Families
Nevada PEP
Families Together in New York State
Oregon Family Support Network
Family Involvement Center
Passages Family Support
Family Support Network
Reestablishing the Village
Family Support Organization of Bergen County
SPAN Parent Advocacy Network (SPAN)
Family Support Organization of Hunterdon, Somerset and Warren Counties
Texas Family Voice Network
Family Support Organization of Passaic County
Texas Parent to Parent
Federation of Families of Central Florida, Inc.
The Struggle Within, Inc
Federation of Families of Florida, Inc.
The Younger Years and Beyond
Federation of Families of South Carolina
The Youth Mental Health Project
Federation of Families, Miami-Dade Chapter Inc.
Tennessee Voices for Children
Foster & Adoptive Parent Connection
Total Family Care Coalition
Georgia Parent Support Network
UPLIFT
Hawaii Families as Allies
Vermont Federation of Families for Children’s Mental Health
HYPED4U Foundation
Wisconsin Family Ties, Inc.
Survey Description:

In March 2019, NFFCMH conducted a seven-question online survey that was sent to 117 FROs. A total of 48 responded to the survey (41% response rate). Questions included both multiple choice and narrative response items. The following report provides a summary of the responses.

Narrative responses are included in this report and are illustrative of the challenges that FROs are facing as they attempt to serve the evolving demographics of family units and the complex child-serving systems that these families are navigating. While this growth can be transformative for an organization, it requires careful planning and management.

Family Run Organizations: Nationwide Services and Supports

Q1: Please indicate which categories of support your organization provides, if “lived experience” is required of the parent/family peer supporters who provide the service and if specialized training is provided for them.

Figure A indicates that, while family peer support is provided by almost every FRO (97.92%) kinship/grandparent, adoptive, and foster family peer support are provided by a large majority of organizations.

Figure B reveals that, while “lived experience” is an important value across FROs, only 65.5% report that this is a requirement for youth peer support.
Figure C While it appears that specialized training for kinship, adoptive, and foster family peers is not provided at the same intensity as parent/family peer support, this data may be impacted by the comment shared by Kentucky Partnership for Families and Children “family includes kinship, adoptive and foster.”

Please share any additional comments regarding the highlights or challenges related to the support your organization provides in these areas.

Federation of Families of South Carolina - We have affinity groups for grandparents and are working to build kinship caregiver support services.

Oregon Family Support Network - OFSN serves all families in need of support, however, we do not have a formal ‘designated’ service for foster families or kinship families. We are involved with discussions in our state re: Kinship Family Peer Support.

Families Together New York State - We provide statewide advocacy and information and referral.

MIKID (Mentally Ill Kids in Distress) - Lived experience does not have to be exactly matched. Kinship and Grandparent Support is offered by trained Family Support Partners that may not be Kinship Caregivers or Grandparents.

Families Inspiring Families - We would like to provide Youth Peer Support. We do not have a youth member on our team right now. If we did, the answers would all be YES.

Families CARE – Other: A parent peer support program for parents who have mental/behavioral health challenges themselves and need peer support for their own mental health needs, as well as parenting skills.

Vermont Federation of Families for Children’s Mental Health - We may not have specialized funding for all the lived experience categories. We support all families who call our 1-800 line for support, although not all PSP’s will have lived experience to match each family member calling.

UPLIFT - We support youth, kinship, and adoptive and foster families via our family support program.

F.A.C.T. - We have Parent Support Partners who support other parents. This includes PSPs who have been foster parents supporting other foster parents. But PSPs are hired because they are parents of a child with a disability, not specifically as a foster parent, etc.

Idaho Federation of Families for Children’s Mental Health - Family Peer Support is about to start in Idaho. We will have a consultant role in the process and bring family voice, but not a delivery role in these services. More likely training, support and evaluation.

Foster and Adoptive Parent Connection - I serve both foster and adoptive parents and kinship families.

Federation of Families, Miami-Dade Chapter Inc. - We can only provide Peer Support to families referred to us by the Department of Children and Families that have an open case with them. We don't have funding to provide support to other families outside of this contract.

Mini Minds Matter - Lived experiences dealing with youth mental illness and trauma. Additionally, supporting veterans with mental illness.

Federation of Families of Florida, Inc. - The staff is trained to provide support to all populations.

Family Support Network - Montana annually hosts the Conference for Abuse and Neglect for all providers working with families. The topics are varied and cover a variety of issues facing families.
Families as Allies - Peer support for special health care needs. We are developing training for other areas beyond the core training, but it is not developed yet.

Family Support Organization of Hunterdon, Somerset and Warren Counties - Family Support Partners support the caregiver of the youth involved with CMO services. Lived experience is required. Grandparents, adoptive and foster families are all families that the FSO works with, but partners don't specifically have to be a grandparent or adoptive or foster family themselves. We provide statewide advocacy and information and referral.

Camden County Family Support Organization - We offer youth leadership, but not youth peer support.

SPAN Parent Advocacy Network - Families whose youth are involved in Juvenile Justice or Child Welfare.

Kentucky Partnership for Families and Children, Inc. - Family includes Kinship, Adoptive and Foster.

Federation of Families of Central Florida, Inc. - Kinship/Grandparent/Adoptive/Foster Peer Support lived experience is not required. However, two (2) staff members have lived experience in those areas and are linked with those families.

Texas Family Voice Network - Our focus is developing family leadership across systems, whether it is specifically toward the family leaders or educating the systems on how to work with families within their work.

Wisconsin Family Ties, Inc. - We provide peer support to any primary caregiver; we don't differentiate between the categories specified above. The training is the same, regardless of the population.

Adults Pushing Forward - We have experience with all scenarios and, if not, have training to be able to meet the need.

Q2: Please indicate if your organization provides support to families parenting children involved in each of these child-serving systems, and if “lived experience” is required of parent/family peer supporters who provide the service.

Figure A Over 90% of the FROs responding indicated that they support families and children navigating behavioral health, juvenile justice, education, child welfare and substance use child-serving systems.
Figure B illustrates that FROs are strongly committed to providing families with support from peers who have navigated the continuum of child-serving systems. As reported, the majority of FROs require system-related lived experience across all child-serving systems.

Please share any additional comments regarding the highlights or challenges related to the support your organization provides in these areas.

Federation of Families of South Carolina - We support families with multiple experiences. We do not have many staff with lived experience in the child welfare system currently, but we do provide support.

Oregon Family Support Network - This is an area where OFSN is currently exploring future development - particularly in the child welfare and early childhood systems.

MIKID (Mentally Ill Kids in Distress) - Lived Experience does not have to be in the system the client family is engaged in. There must be a connection to Medicaid Behavioral Health system in addition to the other systems for us to be able to get paid for our services. Otherwise, we only offer Parent Support Groups and information and referral.

Idaho Federation of Families for Children's Mental Health - We work with youth with intellectual challenges, IF they also have a behavioral health diagnosis.

Vermont Federation of Families for Children’s Mental Health - Vermont is a small state. We serve whoever calls us. We may not have funding for every category of peer support; however, we’ll serve every family who calls. All our PSP's must have lived experience and are trained, although we cannot ensure a perfect match of lived experience between every family served and PSP.

Families CARE - Ideally, we would have lived experience in all the areas above and specialized training as well.

Foster and Adoptive Parent Connection - Support is for the parents or families for child advocacy.

Mini Minds Matter - Working as a SPED teacher, I deal daily with parents supporting them and their children academically, socially and emotionally.

F.A.C.T. - While specialized training may not be offered in some areas - resource development and communication support and information is offered in all categories.

Family Support Organization of Hunterdon, Somerset and Warren Counties - Family Support Partners must have their own lived experienced, so any of the lived experience categories could qualify them. Example: they may have raised a child with mental health challenges, but not substance use - they are still meeting the criteria to work with those families as well.

The Struggle Within, Inc. - Setting footprint and financial backing.

SPAN Parent Advocacy Network - We have staff who have experienced each of these systems working with families in these areas, but not everyone who supports families in each area is required to have lived experience with EVERY system.

Kentucky Partnership for Families and Children, Inc. - "Behavioral Health" lived experience is the ONLY requirement.
Texas Family Voice Network - Working with families whose children are affected with physical challenges, our focus would be on integrated care including mental health challenges or dual diagnosis. It has been a challenge to identify families with early childhood experiences. The focus has been on mental wellness.

Wisconsin Family Ties, Inc. - We serve any of these, if the child has social, emotional, or behavioral challenges. The lived experience we require is not necessarily in each of the specified systems, although we train our staff in navigating those systems.

Maryland Coalition of Families - Problem gambling.

Q3: Please indicate all the categories where your organization does NOT currently receive targeted training that is needed to enhance staff skills and improve support services.

While FROs are providing peer support for a variety of family units and across multiple child-serving systems, 31% - 55% report that they are not currently providing specialized training across 10 child-serving systems. Per the narrative comments, several FROs are in the process of providing or accessing these trainings.

Please share any areas where training is needed that were not mentioned above as well as any additional comments.

Oregon Family Support Network - FRO's serve families in all systems - however the field of family peer support has not yet expanded into these sub-specialty areas of focus.

Families Inspiring Families - We work closely with our region and have access to all kinds of training usually without cost. We have received training in all these areas.

Vermont Families for Children’s Mental Health - If we don’t offer a standard training on these topics, we know where to request the additional training in our state.

Mini Minds Matter - Peer support.

Family Support Network - Parent engagement, Boundaries.

Families as Allies - We are developing these.

Total Family Care Coalition - Trauma.

SPAN Parent Advocacy Network - We are engaged in all the systems above and provide a comprehensive training for all our staff members and volunteers regardless of project or area of focus.

Federation of Families of Central Florida, Inc. - These trainings will be provided in the very near future.
**Q4:** Beyond Parent/Family Peer Support, please tell us what other services your organization provides.

FROs indicate that they are actively involved in several, core areas of support and training for families and youth.

### Please share any other services your organization provides.

**MIKID (Mentally Ill Kids in Distress)** - Specialized services to custodial caregivers of children removed from the caregiver’s care by protective services.

**Families Inspiring Families** - We provide Youth Crisis Response Services to families in crisis.

**Families CARE** - Family Outreach/Peer activities and events and referral.

**Vermont Federation of Families for Children’s Mental Health** - We no longer offer support groups; we offer workshops on specific topics to existing support groups when requested.

**Nebraska Family Support Network** - Our staff members serve on committees and workgroups throughout the systems we serve.

**Federation of Families, Miami-Dade Chapter, Inc.** - Triple P Parenting, Afterschool Program at a middle school, Self Care and Enrichment workshops at our Center.

**Federation of Families of Florida, Inc.** - Mentoring, Summer Camp, Community Engagement, Community Gardening, Food Pantry, Open Table Faith Model, Coordination of System of Care.

**Allegheny Family Network** - Employment Specialist and Housing Specialist, Fathers support groups and trainings.

**Family Support Network** - Parenting classes.

**Total Family Care Coalition** - Capitol City Youth MOVE

**Tennessee Voices for Children** - Clinical therapy

**Camden County Family Support Organization** - Youth Leadership Groups

**Kentucky Partnership for Families and Children, Inc.** - Youth Leadership Trainings; Youth Peer Support

**Federation of Families of Central Florida, Inc.** - I.E.P. Trainings, System of Care Trainings, Youth Mental Health First Aid Training, WRAP training, Warmline Support, Monthly Family Educational Mtgs, Self-Care, Saturday Respite

**Georgia Parent Support Network** - Therapeutic Foster Care

**Wisconsin Family Ties, Inc.** - Training of child-serving professionals.

**ASK Family Services** - Youth Peer Support, Youth Move Chapter, SibShops

**Adults Pushing Forward** - Anger management, grief counseling, shoplifting, job readiness and a few others.
Q5: Please share additional comments regarding the highlights or challenges related to the support your organization provide outside of peer support.

MIKID (Mentally Ill Kids in Distress) - MIKID also provides school and community-based Suicide Prevention and Mental Health First Aid that is not funded by anyone in AZ. It is funded by community donations, grants and admin dollars. Families Inspiring Families - Our state recently added Peer Support to the Medicaid menu. The reimbursement does not cover basic cost of service.

Vermont Federation of Families for Children’s Mental Health - Training funding is hard to come by and is the first to be cut in hard times. It is hard to get funding to just train families.

Family Support Organization of Passaic County - 1 - We need more help with tangible tip sheets or best practice models for teaming well with care management/wraparound facilitator organizations. 2 - We need not profit management and strategic planning training opportunities to diversify funding and strengthen the organization.

The Struggle Within, Inc. - Receiving financial support and grant writing.

HYPED4U Foundation - Finding affordable space or a building to use on a regular basis to host support groups, classes, and events. Finances are a challenge since the organization depends mostly on donations. We need a grant writer that is affordable.

Idaho Federation of Families for Children’s Mental Health - We are lacking many mental health services so knowing how to help a family can be challenging because the services and resources needed frequently don't exist.

Foster and Adoptive Parent Connection - Families need childcare services when they attend support groups or training, especially foster, adoptive and kinship where they are the only ones for support.

Nebraska Family Support Network - We are constantly looking for funding.

Mini Minds Matter - Having finances to provide quality trainings and opportunities in the community.

Federation of Families of Florida, Inc. - Funding is always a stretch.

Allegheny Family Network - We provide childcare and bus tickets for our events, trainings and support groups and stipends to parents who share their expertise.

Texas Parent to Parent - Highlights: Training for Medical Residents & Students 4 Conferences a year Challenges: Services to refer families to.

Family Support Network - Ability to hire trained staff and wages and benefits high enough to keep them.

Families as Allies - We do a lot of provider training on family-driven practice and education advocacy.

Total Family Care Coalition - Challenge is always funding and trying to become Medicaid billable.

Family Support Organization of Hunterdon, Somerset and Warren Counties - We must work within a very tight budget, so sometimes that alone is the challenge when there is something we would like to do with our youth who are in our youth partnership.

SPAN Parent Advocacy Network - Never enough money to provide these various types of support. Many varied cultural, racial, ethnic, language groups in our state that require targeted activities, but the end result is amazing! We had our biannual Parent Leadership Conference last Saturday where 320 diverse parent leaders (even dads!) who are leaders in all the systems mentioned above came together to learn, share, etc. Inspirational!

Federation of Families of Central Florida, Inc. - Funding to increase respite.

Georgia Parent Support Network – Funding

NAMI New Hampshire - While we offer a robust array of supports, and have a talented staff and dedicated volunteer pool, need always far exceeds our capacity to fill it. Advocacy is really important, but there are few sustained funding supports for advocacy efforts.

Adults Pushing Forward - Grants are needed to provide free services and supplies on a continual basis.
Q6: Does your organization provide support to families parenting a youth in the following age ranges?

Families are receiving support across an increasingly greater age span than previously reported. FROs are now providing support from early childhood through adulthood with the majority of support occurring during school age and transition age. Narrative comments indicate that states have varying definitions “adult”, as does Medicaid and states.

Please share any additional comments regarding the highlights or challenges related to the support your organization provides in these areas.

**Oregon Family Support Network** - Families who are supported in our organization receive support regardless of their child’s age.

**MIKID (Mentally Ill Kids in Distress)** - Adults only up to 25 as part of Transition Age program or a Parent of identified child/youth client in the AZ Medicaid Behavioral Health system.

**Families Inspiring Families** - For Peer Support we serve youth up to the age of 19. For Youth Crisis Response, we serve youth/families up to the age of 25.

**Vermont Federation of Families for Children’s Mental Health** - We primarily support school age and transition age. Although we are increasingly supporting families with children 0-5 with extreme behavioral challenges.

**Family Support Organization of Passaic County** - We would do birth to 5, but we don’t often receive referrals for this age group.

**The Struggle Within, Inc.** - Active participation. Accessibility to grant funding to do what I know I can be successful doing.

**Federation of Families of Florida, Inc.** - We serve the entire family and collaborate with other agencies to assist families.

**North Carolina Families United** - Young adults up to age 26.

**Allegheny Family Network** - Only adults up to age 26 if still receiving services and living in their parent’s home.


**Champions for Children’s Mental Health** - Medicaid serves individuals up to age 21, however, Delaware legislation only allows Medicaid to serve up to age 18.


**Kentucky Partnership for Families and Children, Inc.** - Young adults up to age 26.

**Federation of Families of Central Florida, Inc.** - Up to age 23.

**Texas Family Voice Network** - Our broad training focus is always in the development of family leaders across systems. We are not a direct service organization. Our emphasis is on the development of family leaders, regardless of the system(s) they are involved in.

**NAMI New Hampshire** - We don’t get many inquiries about birth to 5 – other organizations specialize in that.

**Adults Pushing Forward, Inc.** - Sometimes transportation.
Q7: As you think about the full range of services your organization provides, are there additional programs or services you would like to highlight or additional challenges you would like to include?

<table>
<thead>
<tr>
<th>Organization</th>
<th>Programs or Services</th>
</tr>
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<tbody>
<tr>
<td>Federation of Families of South Carolina</td>
<td>In past couple of years, we’ve begun providing Wellness Recovery Action Plan (WRAP) trainings to families and youth. I think this can be lucrative for organizations as we’ve had professionals request that we provide the training.</td>
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<tr>
<td>Oregon Family Support Network</td>
<td>Early Childhood - Supporting parents transitioning from Pre-K services to K-12, Supporting parents who are commercially insured - this has become more limited as funding for direct family peer support has been exclusive to wraparound and other Medicaid services more commonly found in public sector. School-based peer support and Community-based peer support would also provide opportunities for more families to receive support and may decrease the need for higher costing behavioral health services throughout childhood and would certainly improve outcomes for children and families.</td>
</tr>
<tr>
<td>Families Together in New York State</td>
<td>Family Peer Advocacy and Youth Peer Advocate training and credentialing.</td>
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<tr>
<td>MIKID (Mentally Ill Kids in Distress)</td>
<td>Higher funding levels in order to pay Peer Supports and other staff wages that are competitive. Walmart, Amazon and many other large employers in our area are paying up to $5 more per hour than we are able to pay for trained Peer Supports and workers that provide direct services to youth.</td>
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<tr>
<td>Families Inspiring Families</td>
<td>We are certified as a Circle of Security parenting facilitator.</td>
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<tr>
<td>Family Support Organization of Passaic County</td>
<td>We would like to do more community awareness and social marketing.</td>
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<tr>
<td>The Struggle Within, Inc.</td>
<td>Transportation and the need to travel and present NFFCMH as a chapter.</td>
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<tr>
<td>F.A.C.T.</td>
<td>We provide Educational Advocacy, are the lead agency for People First St. Charles, and then also have an eligibility specialist to help families get through the Department of Mental Health eligibility process.</td>
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<tr>
<td>Idaho Federation of Families for Children's Mental Health</td>
<td>We do not have parent or youth peer support in Idaho yet (there is limited Family Peer Support that was not rolled out well) which is a challenge when trying to find good family supports. Many of the therapeutic services needed are also not rolled out yet so the CANS identify the needs of the families, but the services are not there to plug them into.</td>
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<tr>
<td>Foster &amp; Adoptive Parent Connection</td>
<td>Webinar support groups are a need, given the circumstance of childcare and transportation issues to identify parents and families’ needs. Transitional services for young adults transitioning out of home.</td>
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<tr>
<td>Nebraska Family Support Network</td>
<td>We would like to get some sort of certification as an organization - not sure what other family orgs are doing in this area. Info would be appreciated.</td>
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<td>Federation of Families, Miami-Dade Chapter Inc.</td>
<td>We would like to provide peer support to &quot;anyone&quot; walking in through the door of our Youth &amp; Family Center, not just provide the workshops offered at the Center.</td>
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<tr>
<td>Mini Minds Matter</td>
<td>Youth support, family resources and life planning skills.</td>
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<td>Allegheny Family Network</td>
<td>We are part of a grant called Steps 2 Connect for supporting the parents of a child that identifies as LGBTQ to help the parent accept the decision of the child promoting safety for at risk youth of suicide. We do research projects with PCORI around family wellness and school.</td>
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<tr>
<td>Family Support Network</td>
<td>Started patient therapy for families and children who have experienced trauma.</td>
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<tr>
<td>Total Family Care Coalition</td>
<td>We are a certified peer recovery provider.</td>
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<tr>
<td>Hawaii Families as Allies</td>
<td>We serve families who are homeless/house less through a partnership with our local family assessment center, a 90-day transitional shelter that works to send families into permanent housing after their stay at the shelter.</td>
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<tr>
<td>Tennessee Voices for Children</td>
<td>We are providing victims assistance, juvenile justice, and school-based services as well.</td>
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<tr>
<td>SPAN Parent Advocacy Network</td>
<td>We have volunteer parents, SPAN Resource Parents, who go through the intensive training that our staff goes through and they provide peer support.</td>
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<tr>
<td>Kentucky Partnership for Families and Children, Inc.</td>
<td>Kentucky Youth MOVE (State Chapter for Youth MOVE National)</td>
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<td>Federation of Families of Central Florida, Inc.</td>
<td>MY Life Youth Group has been very successful in Orange, Seminole &amp; Osceola Counties. Great partnership with Magellan Complete Care.</td>
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<tr>
<td>NAMI New Hampshire</td>
<td>There are many areas we would like to add but in particular transition age youth who are justice involved.</td>
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<tr>
<td>ASK Family Services</td>
<td>We are working on partnering with our CMH to begin providing more intentional transition services following the TIP model.</td>
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Summary:

As the data reflects, family-run organizations have significantly expanded their supports to a much broader demographic of families and their children. Many FROs now navigate the breadth of child-serving systems and support children, youth and young adults across multiple diagnostic profiles. This evolution is challenging the capacity of FROs to meet the hiring and training needs of an expanding workforce. As this new generation of families looks to the FROs for services and supports, the need to create new partnerships and identify new funding streams is of paramount importance.

Implicit in this evolution is the need for a more heterogeneous mix of family peers to ensure fidelity to the value of “lived experience”. As noted in the data, many FROs are currently addressing this challenge while others are struggling to make this shift.

Q7 is particularly instructive as it illustrates the myriad of services and supports that the FROs are providing in an attempt to meet the needs of their communities. This commitment to meeting needs is taxing already limited resources and can overwhelm the capacity of the organization if additional funding and training opportunities are not available. To ensure that this expansion of services and supports to families is successful, the FROs will need strong partnerships with funders, child-serving agencies, and community leaders.