



**FAMILY AND YOUTH INVOLVEMENT IN
THE CHILDREN'S BEHAVIORAL
HEALTH SYSTEM**

Effective Date: 10/01/16



I. GOAL (WHAT DO WE WANT TO ACHIEVE THROUGH THE USE OF THIS PRACTICE TOOL?)

1. To define quality family involvement as a necessary and effective component to the AHCCCS System of Care.
2. To define roles that are uniquely intended for parents/caregivers of children receiving services; youth and young adults who receive or have received services.
3. To describe the roles that family-run organizations play in optimizing family involvement and roles for parents/caregivers, youth and young adults who receive or have received services.
4. To set the expectation for culturally and linguistically responsive practice.
5. To present a wide array of family involvement opportunities.
6. To prepare and enable the AHCCCS System of Care to build and sustain the infrastructure and culture to support and involve family members at all levels of the system.

II. BACKGROUND

Arizona holds a distinction in the United States for promoting various family roles in relation to the AHCCCS System of Care. The involvement of families is credited as making a significant contribution in improving the service system. This Practice Tool presents a review of the various roles that families may and do play within the AHCCCS System of Care.

This Practice Tool is organized around three roles for families:

1. First, families are encouraged and supported to participate as active and respected members of their child's Child and Family Team (CFT). In that capacity, families influence the development and implementation of a Service Plan that will respond to the unique strengths and needs of the child and family.
2. Second, families participate in various activities that influence the local, regional and state service system. This type of activity is commonly called "Family Involvement". Family members have first-hand experience and are able provide a unique perspective and insight. In addition, in Arizona family members have representation on boards, advisory committees and policymaking groups, and are partners in the development and implementation of programs and policy to improve the AHCCCS System of Care.
3. Third, family members may work in a professional capacity in the AHCCCS System of Care. In this capacity, family members offer a special type of support (peer-

delivered) to the families and children that they serve. Further, families who work in the system may also influence the service system in which they are a part by contributing the family perspective to the service environment.

Refer also to Attachment A, Family and Youth Involvement in Children's Behavioral Health System Desktop Guide.

A. RECOMMENDED PROCESS/PROCEDURES

This Practice Tool discusses how families can be supported successfully in their assumption of the general roles listed above. The following is a more detailed listing of roles for families in the Children's AHCCCS System of Care:

1. Family Participation in Service Planning:
 - a. In accordance with the Arizona Vision and 12 Principles as outlined in AMPM Policy 430, the first Principle, Collaboration with the Child and Family is the foundation for the mandate that all children served by the Children's AHCCCS System of Care have a CFT. Through the team process, parents/caregivers and youth are treated as full partners in the planning, delivery and evaluation of services. The team process is most effective when the family is welcomed (access), empowered to have a strong voice (voice) and has a thorough sense of commitment to the plan that they have created (ownership). Even though this participation is only on an individual basis, it is an example of family involvement, which brings about quality service for the child and family. Effective CFTs have a broader system impact by serving as an example for other CFTs.
 - b. Through the CFT process with respect to service planning, families must be able to access services tailored to their unique needs and circumstances based on the families' individual culture which goes beyond race and ethnicity. They should not be expected to fit their needs into a list of categorical services. Special care and attention needs to be paid to the families' readiness to receive potential services being offered, and should be explored before putting services and supports in place.
 - c. The CFT must honor and give careful consideration and weight to the family's preference to end one service and/or request another. Families should feel free to express their concerns without consequences.
2. Challenges or considerations for this family role: Historically in AHCCCS System of Care, the implementation of the first of the 12 Principles, collaboration with the child and family, has often not been as full and complete as desired. Even now, while recognizing the benefits of this collaboration, our system sometimes struggles as professionals learn to embrace this approach. This is for a variety of reasons:
 - a. Staff members, including supervisors and leadership, may vary in their understanding of what constitutes true collaboration between professionals and families. Although a basic tenant for the AHCCCS System of Care, this Principle is not taught consistently in educational settings for behavioral health staff receiving professional training. Where there is not consistent understanding to the

- principle of partnership with the parent and child, the experience of the parent, child and team can suffer,
- b. Families vary in their capacity to know what they need and to communicate these needs effectively. This can happen for a variety of reasons. The youth’s challenges can be complex and the family situation can also be complex. In addition, the environment the family comes from (family, community, work situation, school, etc.) can create an unfair burden of guilt and self-blame, which can lead parents/caregivers, children and youth to feel that many of their challenges are their “fault”. When the family feels the challenges are their fault, they have a harder time asking for resources to assist with these challenges,
 - c. When they encounter individuals within the AHCCCS System of Care who do not appear to embrace this Principle, families may not know where to go to express their concerns or may be uncomfortable expressing their concerns,
 - d. Some CFTs include a Family Support Partner (FSP)/Parent Partner (PP) (see below) who can assist the parent with their participation. Although some families are very capable to express their perspectives, others cannot. When this is the case, some type of adjustment in the CFT process, either through staffing or through the role of the facilitator, is needed, and
 - e. When individuals do not recognize the value of family-professional partnerships, including paying particular attention to shared power in the relationship, joint decision making, problem solving and mutual accountability.
3. Family Involvement in Local, Regional and State Systems
- a. Family involvement opportunities should be available throughout the AHCCCS System of Care. Family leaders will represent the family perspective as participants in system transformation activities, including but not limited to:
 - i. Policy and program advisory committees,
 - ii. Trainings for families and professionals,
 - iii. System monitoring,
 - iv. Leading focus groups, conducting satisfaction interviews and other new initiatives related to family involvement and family support,
 - v. Identifying, developing and supporting, coaching and mentoring emerging and existing family leaders,
 - vi. Distributing information about resources to families.
 - b. Generally, family member roles are within formal structures reflected in procedures and policies. They are formalized in documents such as contracts or agreements within in the service system, (articles of incorporation, by-laws, founding documents, Memorandums of Understanding, etc. These elements assure family involvement continues even when there are disagreements in perspectives. An important element is that the structures created for family involvement reflect a value placed on the family perspective; which include:
 - i. A range of persons who are engaged in Family Involvement activities (parents, caregivers, extended families, siblings and youth, and other natural supports).
 - ii. A budget for family involvement is clearly identified. For example, family members are compensated for their time and travel, there are funds dedicated

to the training and support of family members who participate in various family involvement activities, etc.

- iii. Opportunities are in a form that indicate that the organization values family involvement (participants are provided information about the topic, meetings are in-person, family input is incorporated in final decisions, meeting times and places agreed upon by families).
 - iv. There are multiple venues for family involvement. For example, families may advise on or deliver a training program; they may participate in a quality management review body; and they may participate in a children's services policymaking group).
 - c. When there are multiple opportunities for family involvement, there is greater expectation that the family perspective will be heard and reflected in the operation of the organization.
 - d. Challenges or considerations for this family role: Family Involvement calls for real change in the way organizations and the system functions. It means power is genuinely shared with family members. For genuine family involvement to occur:
 - i. Decision making needs to be shared with families.
 - ii. Organizations need to be able to partner with families and have an open line of communication with them. This may simply mean that systemic jargon is discarded and the issues are discussed in everyday language.
 - iii. There are sometimes costs associated with the involvement of family members within the above scope. These can include such things as time, travel and preparation. While compensation paid to a family member when performing these role(s) is not mandatory, it can often be beneficial especially when all parties at the table are compensated.
 - iv. Problem solving and negotiation for a solution shall be part of the process.
 - e. Families requiring assistance often need training on the following, including but not limited to:
 - i. The terms used in the work,
 - ii. How to read financial statements or quality management reports,
 - iii. Background on policies or programs, and
 - iv. Organizational structure and decision making process.
 - f. Family-Run Organizations are often a resource to families to train and support them in these roles. In order for families to be truly independent and significant contributors to the system, they need to have a safe and supportive place where they can receive assistance in carrying out this role. In addition, families are strengthened in their Family Involvement role when they can connect with other family members to interact and exchange views. Family-Run Organizations are a place where this can happen.
4. Family Work Roles in the Children's AHCCCS System of Care
- The AHCCCS System of Care offers many opportunities for parents/caregivers, youth and young adults to participate at all levels as family and system resources. As stated above, the AHCCCS System of Care has been enriched through the array of contributions that family members have made in their work within the system. Some

roles for family members involve full-time or part-time employment, while others may offer stipends for participation. Flexibility and sensitivity are essential in determining how to best compensate the family member for their contribution.

The following is a brief list describing the functions or roles:

FSP/PP - This is a parent or primary caregiver with lived experience who has raised or is currently raising a child with emotional, behavioral, mental health or substance use concerns. The FSP/PP will assist the parent/caregiver of a child, who is receiving services, to identify needs and communicate those needs to the team so that the family's perspective is well represented in the child's Service Plan. Part of this role may be to exercise non-adversarial advocacy to assure that the family's needs are addressed in planning. On behalf of the family, the unique role of the FSP/PP may involve assisting the family in sharing their perspective to meet their needs that are addressed in the plan. The FSP/PP will further assist the family to assure that the plan is implemented and progress is made. Finally, the FSP/PP will assist the family to achieve self-efficacy resulting in decreased reliance on the formal system.

Youth Partner - This is a young adult who has received services in the AHCCCS System of Care. The Youth Partner provides support and services to youth who are receiving services from the system. This role is used primarily for work with older teens who are transitioning to the adult AHCCCS System of Care.

Greeter (Connector) - This is a parent or primary caregiver with lived experience who has raised or is currently raising a child with emotional, behavioral, mental health or substance use needs. This person's role is to welcome a new family during the time of intake to the AHCCCS System of Care. Since this can often be an intimidating time, the Greeter can offer support and information to the family by telephone or in person to give reassurance during this difficult time. Another supportive resource for families is other parents/caregivers who also have a child receiving behavioral health services. Often this connection is made through parent support groups. The Greeter can help the parent to become involved in such a group.

Navigator - This is a parent or primary caregiver with lived experience who has raised or is currently raising a child with emotional, behavioral, mental health or substance abuse needs. The Navigator is sometimes called an advocate and often works through telephonic support. This person assists the parent/caregiver in working their way through various child serving systems including behavioral health, Child Protective Services, Juvenile Justice or the school system. This person's knowledge of the child serving system and relationships can be a resource to help the parent of the child receiving services to understand the expectations of the applicable system. This knowledge can often be a resource for families to obtain answers or services in areas beyond behavioral health.

Telephone Support - This is a parent or primary caregiver with lived experience who has raised or is currently raising a child with emotional, behavioral, mental health or substance abuse needs. Families in the AHCCCS System of Care often need advice or direction in the many challenges they face. Through telephone support, families can often get the help they need. This support may vary including:

- a. Coaching on how to make an initial contact to obtain behavioral health services
- b. Provision of information about a behavioral health diagnosis
- c. Provision of information about benefits or resources for treatment or medication
- d. Information about special education or other school issues

Family Interviewer - This is a family member having had at least one year of experience with the Child and Family Team process. With the implementation of the Practice Improvement Reviews in the AHCCCS System of Care, there are now opportunities for parents/caregivers to be employed to conduct interviews. The parent perspective is a valuable asset to this role. It is a good example of how parents/caregivers add value to the system.

Family Trainer - This is a parent or primary caregiver with lived experience who has raised or is currently raising a child with emotional, behavioral, mental health or substance abuse needs. The Family Trainer provides training to staff and to parents/caregivers on various behavioral health topics. There are numerous topics in the AHCCCS System of Care where parents/caregivers or youth can offer a fresh and rich perspective on the topics. Example topics include: Child and Family Teams, Direct Support Services, and various parent work roles such as Family Support Partner and Parent Partner.

Community and Family Integration Coordinator/Consultant - This is a family member who promotes family access, voice and choice at all levels of the system. This individual creates opportunities for youth and families to partner with professionals, welcomes and engages families, and encourages their partnership in the sharing of ideas and connection to community resources. In addition, the Community and Family Integration Coordinator/Consultant collaborate with local family-run organizations to promote family voice, family-driven care and family involvement at the local, state and national levels.

Family Members/Youth/Young Adults Serving on Task Forces, Committee Groups, Etc.- These family/youth members bring a unique perspective and out-of-the-box thinking, along with their personal life expertise, to the decision-making process in conjunction with professionals who bring their technical expertise to the table. The collaboration and interaction within this group create an authentic family-professional partnership in which both are treated as equals and collaboratively bring an enriched understanding of the needs of families as well as establishing meaningful family involvement.

NOTE: In smaller providers, these parent roles may be combined and assumed by one person. In larger providers, there may be much more specialization.

These roles are described to give an impression of the types of functions family members can play. This is not meant to imply that each role must be assumed by a separate individual.

5. Parent/Caregiver/Youth/Young Adult Delivered Support or Service Considerations for family members working within the system*

As noted in the section above, there are many roles for families within the system. Not all of them are direct support roles, as delineated in the Family Involvement section of this Practice Tool, but those that are direct support have common characteristics. Please note for the purposes of this section, this role will be called Parent/Youth Partner.

As direct support staff Family Support Partners/Parent Partners and Youth Partners share the following characteristics.

- a. Provide direct person to person work with family members or youth receiving services. This is a range of roles/functions including; providing support, helping people learn new skills, accessing resources and providing family education.
- b. Using personal experience to enhance the relationship: Parent/Youth partners have to be prepared to share their personal story or experiences when appropriate. Extension of self is one way that peer support roles differ fundamentally from other supportive system roles. Training will be readily available to Parent/Youth Partners to validate the optimal way to offer their experience as a resource.
- c. Collaborative model of problem solving: There is no expert in a parent-to-parent support role. The decision making model is a shared model in which the peer parent and the family jointly make decisions that blend the information the Partner brings to the table with the family's expertise on their own situation,
- d. Shared first-person system experience: Parent/Youth Partners have first-person system experience and are able to share, compare and connect with the experience of the family as they are going through the system,
- e. Support to hold a different perspective: Parent/Youth Partners bring a different perspective to the way services and systems operate. Effective Parent/Youth Partners are sustained by an organizational commitment that demonstrates the ability to appreciate different perspectives. In other words, family members can hold different opinions.

Parent/Youth Partners can flourish when the provider demonstrates coherence with the role and unique perspective of that position. This means that the organization, in addition to demonstrating a commitment to family involvement, also demonstrates the organizational capacity to support the uniqueness of this role administratively and programmatically. Examples of this include:

- a. Administrative Supports: Ability to recruit parents/caregivers and young adults who have first-person experience as well as providing orientation, necessary tools etc. Other administrative supports may include:
 - i. Ability to connect with others who have first-person experience: Persons in these roles benefit from an ability to network with others, both inside and

- outside their organization, in similar circumstances. Organizations employing Parent/Youth Partners should build the capacity for these connections to happen.
- ii. Promotes choice for advancement: Parent/Youth Partner roles shall have opportunities to advance while not giving up their ability to contribute their unique perspective in their work. This means that in order to get promoted the worker should not have to change job roles (such as moving into a case management role) but is able to move ahead while staying in a family/youth partner role. On the other hand, if the employee desires moving into other types of roles the organization should create solid career paths for that to happen.
 - iii. Values Personal Experience: The organization shall demonstrate an organizational commitment to the personal experience of family members. This means that salary scales are based on more than formal training but also have the capacity to take into account first-person experience in setting salary ranges.
 - iv. Accommodations for Personal Experience: The organization shall demonstrate a commitment to the personal experience of parents, grandparents, caregivers and young adults employed in these roles by offering flexible schedules, unique employee assistance options for people in the Parent/Youth Partner roles, flexible family leave policies and, in the case of families with youth/children in the system, flexibility for sons/daughters to be welcomed into the workplace.
- b. Programmatic Supports: Supports in this category reflect the willingness to blend perspectives and to value first-person experience along with formal training. These may include:
- i. Appreciative Capacity of Supervisor: Supervisor shall be able to demonstrate a sincere and authentic strength based appreciation of the Parent/Youth Partner. The supervisor must support growth and development of each Parent/Youth Partner to help them realize their professional goals. Often the most successful supervisors of Parent/Youth Partners are those who are also a parent/caregiver of a youth who is receiving or has received services in the AHCCCS System of Care.
 - ii. Strong commitment to protect the integrity of the role: Organizational supervision, management and leadership shall demonstrate a commitment to preserve the integrity of the role and the unique perspective brought by first person experience.
 - iii. Ongoing commitment to assuring equal status: Those who come into paid roles within the formal system may run the risk of being seen as secondary players. The provider should demonstrate the ability to insure this position is as valued as those positions that represent formal training versus personal experience.
 - iv. Meaningful and Independent Roles: Programmatically, these positions are involved in providing direct support to a parent/caregiver or youth which may include education, resource access and development, non-adversarial advocacy or skills development delivered in a group, individual or family setting. The provider will demonstrate the ability to allow these roles to play a meaningful role with families.

B. FAMILY-RUN ORGANIZATIONS

For decades Family-Run Organizations have offered parents/caregivers of children with behavioral health challenges a range of services and supports. Inherent in the identity of Family-Run Organizations is the natural ability and necessary environment to link families with individuals in their communities who share similar experiences in their life's journey. Without these peer connections to other families, stigma may create isolation, self-blame and other unneeded barriers that prevent families from reaching out and connecting with available supports and services. The growth of the family's natural support network is an important means for achieving higher levels of community integration and decreasing reliance on formal services. An important benefit of this informal family-driven network of support is the opportunity to build sincere, authentic lifetime connections.

In Family-Run Organizations, parent/youth support happens in a variety of ways and through a variety of strategies. It is recommended that each family be connected with a Family-Run Organization as soon as they are enrolled, to receive informal support and to learn how to access the type of support that is meaningful for them; for instance, some families experience healing through connection with other families in a support group format. Other families find resiliency, recovery, and balance through connection with an individual who has a similar story to tell. Some discover their own capacity for resilience in fellowship with others in a social or training setting, or may need one-on-one support to achieve a specific outcome as identified by the Child and Family Team within the context of individual cultural environments and needs.

Family-Run Organizations are seen as "safe places" in the community for parents and youth to process/discuss their challenges and to seek solutions through services or through systems change. It is a place where families learn how the behavioral health and other child-serving systems work; how they can articulate the issues that concern them, and parents and youth who participate in committees or boards are able to obtain on-going support to continue and grow in this role.

Family-Run Organizations provide a leadership role in, not only building family support and involvement, but in system development or transformation at all levels. Through leadership and technical assistance activities on systems transformation, Family-Run Organizations assist in developing and connecting the "authentic" family voice to shape sustainable systems transformation. This technical support and leadership is instrumental in the family-professional partnerships throughout the systems. By building a mutual partnership, which is characterized by interdependence and cooperation, family members and behavioral health professionals are able to improve service, the quality of opportunities available, and change the values and attitudes of society toward children with emotional, behavioral and mental disorders. Family Run Executive Director Leadership Association (FREDLA) serves as the national representative and advocate for family-run organizations. FREDLA acts as the Family Engagement Hub for the Network, providing resources, training, and technical assistance to federally funded System of Care communities/states and non-funded communities/states.

National research indicates there are nine key components and characteristics of effective and sustainable family-run organizations. These are described by the Research and Training Center for Children’s Mental Health at the University of Southern Florida as follows:

1. **Values** – The value of family partnership is evident, with families and youth involved in all aspects of the system in a variety of capacities, including setting policies, developing programs, delivering services, providing training and technical assistance to enhance/expand family partnerships across the AHCCCS System of Care.
2. **Leadership Development** – Family-Run Organizations recruit, engage, and nurture diverse family leaders and nurture their development as a leader to interface effectively with the AHCCCS System of Care in a variety of capacities
3. **Partnerships** – Families and youth are encouraged, supported and paid to participate in all operations of the AHCCCS System of Care, including setting policies, developing programs, delivering services, providing training and technical assistance and assessing the impact of AHCCCS System of Care on children, youth and families served, agencies and systems and the community.
4. **Access and Referrals** – Family-Run Organizations are adequately funded and supported to develop and sustain a diverse group of families who collectively and effectively are the “family voice” in shaping their community’s response to children with mental health needs and their families. In order to accomplish this goal, Family-Run Organizations must make themselves accessible to all families.
5. **Meeting Family Needs** – The primary role and responsibility is to meet the needs of families. They do so by helping families in a peer support role to access services, by addressing requests of all families about their systems of care community, by helping families have direct connections to mental health providers and other child serving agencies; and by helping develop skills and knowledge of families in changing policy.
6. **Productive Working Relationships** – Family-Run Organizations have productive working relationships with state and local agencies and with providers in order to strengthen policy commitment and service delivery to children with mental health needs.
7. **Sustainability and Growth** – Mechanisms are in place to sustain a Family-Run Organization. Funding and in-kind support from multiple and varied sources are important to the sustainability of these organizations.
8. **Youth Involvement** – The development of youth leadership opportunities and organizations. Youth are encouraged and supported to participate in all operations of the AHCCCS System of Care, including setting policies, developing programs, delivering services, and assessing the impact of the AHCCCS System of Care on children, youth, and families served.

9. **Organizational Progress Chart** – This is a tool to guide the growth and progress of the Family-Run Organization to review the challenges/barriers at the various levels of development.

Throughout the country, Family-Run Organizations provide an important function in systems development by supporting, mentoring and connecting parents and youth to become spokespersons and leaders.

Through the Family-Run Organizations, parents and youth receive education and training about the organization and availability of services, funding, data collection, quality improvement initiatives, and policy or legal considerations that affect how families and youth with behavioral health needs are served. Family members serving in these roles are increasingly recognized as valued and necessary partners in working with leadership at all levels to bring positive change to the AHCCCS System of Care. Similarly, the Family-run Organizations are providing increased technical assistance and leadership on family support, family involvement and systems transformation topics at the local, state and national levels.

1. How families grow in their capacity to become involved or to be a service provider:

Parents/Caregivers who are raising a child with behavioral health challenges often travel a journey of personal growth and change. At points along this journey, parents/caregivers may feel ready to take advantage of opportunities to become involved in the AHCCCS System of Care through participation in family involvement activities or through employment in the AHCCCS System of Care. Keys for Networking, a Family-Run Organization in Kansas, developed a 10 step tracking system measuring each parent's growth as they are supported and face new challenges with their child. This system illustrates how parents/caregivers grow, change and become candidates for family involvement or family employment opportunities. It also illustrates the role a Family-Run Organization plays in helping each parent along this journey.

The following is a list of the ten steps associated with the process:

- Step 1: Seeks Information,
- Step 2: Initiates additional contact,
- Step 3: Commits to address problem,
- Step 4: Works on the problem,
- Step 5: Resolves initial problem/feels success/accomplishment,
- Step 6: Takes on new problems,
- Step 7: Offers to help others,
- Step 8: Completes training to help others,
- Step 9: Helps others,
- Step 10: Impacts local, state, national policy.

Parents/caregivers move through these steps at different paces based on differences in their personal and family circumstances. At each step, the Family-Run Organization can offer parents/caregivers opportunities for growth. In addition, the Organization has an obligation to offer support and reassurance at each step as families face each day's challenges. As parents/caregivers grow in their mastery over the struggles they face, they often grow in their motivation to assist and support other parents in their journey. This motivation is a rich potential resource to the Children's AHCCCS System of Care. Great payoff can be gained from these families when they are able to work in a context where they are valued and supported.

2. Capacity Expectations

Because family involvement and family support are critical to systems transformation, the number of Parent Partner and Family Support Partner positions should increase as the system builds capacity. In a fully developed system, additional family roles should be incorporated in the staffing requirements to build and sustain family involvement. Providers should hire a diverse cadre of staff that is reflective of the community they are serving.

3. Anticipated Outcomes

Anticipated outcomes include:

- a. To define quality family involvement as a necessary and effective component to AHCCCS System of Care,
- b. To define roles that are uniquely intended for parents/caregivers of children receiving services; youth and young adults who receive or have received services.
- c. To describe the roles that Family-Run Organizations play in optimizing family involvement and roles for parents/caregivers, youth and young adults who receive or have received services.
- d. To set the expectation for culturally and linguistically responsive practice.
- e. To present a wide array of family involvement opportunities,
- f. To prepare the AHCCCS System of Care to build and sustain the infrastructure and culture to support and involve family members at all levels of the system, and
- g. Increased statewide practice in accordance with the Arizona Vision and 12 Principles.