THE EVOLUTION: FAMILY-DRIVEN CARE AS A PRACTICE

A Practical Guide on Understanding Family-Driven Practice on All Levels

NFFCMH

National Federation of Families
for Children's Mental Health

Melanie Funchess
Sandra Spencer
Marie Niarhos

Introduction

Family-driven, as a value, has long been a cornerstone of our work in Systems of Care. We dedicate significant time to recognizing families and making sure they are at the table and have a voice. We make sure that families receive compensation for their work. We say that families are primary decision makers in the lives of their children, but is this the essence of family-driven care? Does this expression of family-driven resonate across cultures? Does it have the impact we desire at all levels?

In this guide we will explore family-driven as a "practice". How does what we do match up with what we believe? Are our actions moving us toward our goal of family-driven "systems"?

MAIN GOALS

This guide has three main goals:

  I.   To provide clarity on the nuts and bolts of family-driven practice.
 II.   To highlight the attributes and characteristics of family-driven practice at the program and policy levels.
III.   To provide examples illustrating how to implement family-driven practices and how communities work toward being family-driven.

WHY THIS GUIDE?

The rationale for this document is simple. Many system of care communities across the country have expressed challenges with operationalizing the family-driven value, having a clear vision for what it looks like, and knowing when it's being practiced effectively.

In this document, we seek to provide a clear framework for family-driven practice. The historical context for the family movement will be described. Concrete examples of family-driven policies will be presented. We will define and discuss transactional vs. transformational practice within the context of family-driven work. We will also explore the concept of empowerment as well as look at cultural considerations in family-driven practice.

This document is not intended to be nor should it be considered to be an end all be all, but rather basic scaffolding for additional learning. As a movement, we must delineate the narrative by which we are defined. By doing this, we ensure the enduring authenticity of the work we do moving forward.

Evolution of the Family Movement and Family-Driven Care

A BRIEF HISTORY

Historically, families were blamed for their child's mental health disabilities. The term "blamed and shamed" was coined by parents to refer to the way society treated families. They first blamed them for all of the child's negative behaviors and then made them feel very ashamed for having caused such bad behavior in their child. It was also a practice for families of children with mental health challenges to be labeled as "dysfunctional" families, again putting the blame on the family. The service system took no responsibility for the lack of positive treatment outcomes for children. The service system was fragmented, families were not given the opportunity to provide input into service planning or evaluation, and there was no easy access to the limited services that were provided. In 1982, Jane Knitzer released a book titled, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services.* This book exposed the truth about the state of mental health care in America and spoke to the need to see families as part of the solution and not as the problem.

Small pockets of progress were being seen across the United States. A training called "Families as Allies" was developed by Portland State University to promote the collaboration between parents and providers in treating children with mental health challenges. In 1989, Portland State University held a "Next Steps" conference as a follow up to the Families as Allies meeting and there it was decided that parents needed to come together in an organized way to address the lack of support and services for children with mental health challenges and their families. A direct outcome of this conference was the establishment of the Federation of Families for Children's Mental Health (now known as the National Federation)… hence the start of the "family movement". The National Federation provided an opportunity for families to have a voice in the way treatments, services and supports were developed. In 1993, the inclusion of family voice was required in the Children's Mental Health Initiative (Systems of Care) Guidance for Applications (GFA).

The voices of families continued to influence that GFA process. In 1999, "family involvement" was required in all grant applications. In 2000, "family professional partnerships" were required and families were invited to work hand in hand with professionals in developing individualized service plans for their child and family, as well as helping to shape the developing of systems of care.

In 2003, the President's New Freedom Commission on Mental Health issued A*chieving the Promise: Transforming Mental Health Care in America*. Goal 2 of that report said that Mental Health Care must be "consumer and family-driven."

The National Federation developed a definition of family-driven. Finally, in 2005, family-driven was written into the GFA as the preferred language for family involvement. The National Federation developed a training curriculum called "On the Road to Family-driven Care." This training was developed as a tool to help communities, systems, and individuals begin the process of thinking differently about the value of family participation in the treatment and outcomes of children with mental health challenges.

Defining Family-Driven Care

WHAT FAMILY-DRIVEN CARE IS "NOT"

We always try to take a strength based approach when discussing issues around family engagement, but, for the purpose of clarity, we are going to take a look at what family-driven care is NOT. We have described what it IS in the working definition of family-driven care: *Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.*

Family-driven care is "not" a tool for families to dictate what everyone should and should not do. Nor is it meant for providers to place the entire decision making on the family. Family-driven practice allows for shared decision making and shared responsibility for outcomes. Family-driven means families have "a" primary decision making role. Notice the word "a." It carries a totally different meaning than the word "the". So the definition does not say that families have "the" primary decision making role, but "a" primary decision making role. This definition was developed in the context of the systems of care philosophy of a comprehensive, community based approach to meeting the needs of children with serious emotional challenges and their families. This approach is accomplished through the creation of child and family teams comprised of family, community and agency representatives who are all critical to providing services and supports to ensure the success of the child and family.   This team not only shares in the successes but also takes responsibility when things don't go as well as planned. Therefore decision making is a team effort with the primary caregiver having a strong, viable voice in the decision making process. The caregiver does not just dictate to the team what needs to happen. The caregiver is involved in the child and family team process to draw upon the resources and expertise of others. Sometimes this is not clear to all members of the team.

Example One

A child and family team was convened to help meet the needs of a child that was being suspended from school several times a month for fighting and other aggressive behaviors. The father arrives at the meeting and tells the team that his son needs to be transferred to a different school and that transportation needed to be provided at the school system's expense. His son also needed a classroom aid assigned to him to help him with his social skills. The father also requested that a different therapist be assigned to his son, because it was obvious that the current therapist was not able to help his son work through his anger issues. And finally the father requested the team find resources to put the son in an afterschool karate class that would teach him control. The father said that meeting these request would show how family-driven this team really was. This father clearly thought he had "the" primary decision making role on this team. This is not the best approach.

Example Two

Another family was enrolled in the system of care as their child was being transitioned back into the community from a year in a residential care facility. The team wanted to make sure the transition was successful back into the home, school and the community. The case manager started the meeting giving an update of the family history and then asked the parents "now what do you need and want us to do to make sure this is a successful transition?" The parents were new to systems of care and had no idea what was available to them. They were expected to lead the team and know exactly everything they needed and what resources and services were available to them. They were not given any information prior to the meeting and were not clear on the roles of everyone around the table. The team thought that asking the family to tell them what to do was being family-driven. Again, the assumption was that the family had "the" primary decision making role. This also is not the best approach.

In both examples, a clear understanding of the definition was needed. The team should work together to identify the needs and strategies to meet the needs with the family being a valued member of the team and seen as crucial in the decision making process.

All members of the team having a clear understanding of the definition of family-driven is a solid first step in helping families on the road to empowerment.

Empowerment

WHAT IS IT?

Empowerment is a concept that is spoken of often in system of care circles. We speak of empowered families advocating and "having a seat at the table" but what does that really look like on the ground in the lives of families? In transformational family-driven practice (transformational family-driven practice represents a style that is exemplified by a shared vision, power and responsibility by both the provider and the family) we strive to ensure that families gain the knowledge about their child's challenges, learn the skills necessary to navigate the systems to gain what is needed for their child, and become empowered to see and articulate their family vision. This is deeper than the traditional view in which families "feel empowered" this speaks to families gaining the skills and ability to change their lives and the environment around them in concrete ways. The following are examples of empowerment on three levels.

- **Practice Level**- A family member being able to advocate, on their own, for services in a school setting or a parent being able to navigate a system, articulate their needs within that system and advocate for a satisfactory resolution.
- **Program Level**- A family member has attained and successfully applied the skills of effective advocacy and now works to share those skills with others as a Parent Support Provider (PSP).
- **Policy Level**- Parent Support Providers sit on state level team to craft policy that authorizes the use of PSPs. Members of the group look to the PSPs as "content area experts" in crafting the qualifications and appropriate roles of a PSP.

This is a process that can be fraught with challenges but is vitally necessary to the sustainability of our families, our communities, and our movement.   Some of the characteristics of empowerment are listed below

- Having decision-making power
- Having access to information and resources
- Assertiveness
- Not feeling alone; feeling part of a group.
- Effecting change in one's life and one's community.

Transactional and Transformational Practice

Transactional and transformational leadership theories are concepts that originated in the business and leadership literature.   For the purposes of this guide we will look at these two models in terms of "family-driven practice." There is a strong parallel to be drawn when looking at family-driven practice. We will define each model, provide examples of them in practice and compare the two in terms of moving us toward family-driven practice. The effectiveness and impact of the work we do with and on behalf of families can be deeply influenced by the style of leadership practice we employ.

TRANSACTIONAL FAMILY-DRIVEN PRACTICE

Transactional leadership practice involves motivating and directing followers primarily through appealing to their own self-interest. The power of transactional leaders comes from their positional power and responsibility in the organization. The main goal of the follower is to obey the instructions of the leader. The nature of the relationship between the leader (provider of service) and the follower (family) is based upon "transactions" or contingent reward. The bond built between the provider and the family is established and built upon this exchange; for example providing assistance or incentive in exchange for attendance at an event or meeting. Transactional leaders overemphasize detailed and short-term goals, and standard rules and procedures. Generally, they do not make an effort to enhance followers' creativity and generation of new ideas. Such leaders tend not to reward or they ignore ideas that do not fit with existing plans and goals. Transactional leaders tend to be directive and action-oriented and their relationship with the followers tends to be transitory and not based on emotional bonds or possessing a shared vision

This practice assumes that followers can be motivated by simple rewards. The motivation between the leader and the followers is based upon the reward or compensation which the followers receive for their compliance and work. The leader believes in motivating through a system of rewards and punishment/withdrawal of reward. If a follower does what is desired, a reward will follow, and if they don't comply with the wishes of the leader, there will be a punishment or a withdrawal of reward.

Transactional practice does not foster a shared vision between the provider and the family. Each partner in the relationship is motivated by the "reward" for the interaction. For the provider, the reward may be obtaining a certain number of attendees to count as having "active family involvement." For families, it can be getting a gift card, stipend, or even an opportunity to have respite from the children. None of these "rewards" build a sustainable base for relationship between the provider and the family. The incentive goes away and so does the "partnership." It can lead to the creation of an environment defined by position, power, perks, and politics. There are more empowering ways to compensate families for their expertise.

TRANSFORMATIONAL FAMILY-DRIVEN PRACTICE

Transformational leadership represents a leadership style that is exemplified by charisma and shared vision between leaders and followers (Burns2010). In terms of family-driven practice, there is power and responsibility on both the provider and the family. The following are examples of how providers and families partner in a transformational practice model:

- Provider's stimulate and inspire families to reach for goals, celebrate with them as they achieve them, and encourage free and creative thought as they reimagine their family and/or the system as a whole.
- Families inspire and stimulate providers to trust in the shared decision making process and release some of the traditional controls. They celebrate with them as they release some of the traditional views of power and embrace a new vision of shared decision making.

Transformational practice has great multilevel reciprocal benefit. Families become empowered by enhancing their vision of themselves and other families like them. This leads to strong, consistent, and fully engaged family voices. Providers benefit by having fully engaged partners in planning both on the practice and on the program level. Systems benefit from having strong sustainable family voices to partner with them as policy is crafted. Constant critical analysis of the behaviors between providers and families will yield great benefits for both.

Building on the Definition of Family-Driven Care

Empowered families are able to look at a situation, evaluate it critically, articulate a position, and have the ability to advocate for change. Policy makers need to be champions of these empowered voices creating opportunities for them to be heard and supporting the growth of empowered family leaders. Other examples include the education of policy makers in how to create safe, open, welcoming places for family voice, as well as learning how to disagree without exploiting the power differential. For example, a family leader and a system leader are in deep disagreement about the possible implications of a possible policy change that is currently being debated. In a transformational model, the two leaders would go back to the shared vision and, based upon that vision, lay out their positions. They would have the following agreements:

- Both partners would assume benevolent intent
- Both partners would be open to the position of the other
- The system leader would not fall back on their positional power to get their way.
- The family leader would not fall back on their social power to get their way.

Then, they would work as equals toward a mutually beneficial solution.

Most challenges arise as we try to implement family-driven care on the policy and program levels. Within the systems that serve children with mental health challenges, there are many variables in deciding who is a part of the team that plans and provides services and treatment for families at the program level and who the decision makers are at the policy level.

On the program level, families often have child and family teams to assist in the coordination of care for their child because of their involvement in multiple systems. Several members of this team are selected by the family as their support system. Other members of the team are a part of the family's provider network (i.e. teachers, counselors), and yet other members of the team may be mandated to be on the team (i.e. probation officers, social workers). During team meetings the family member who is the primary caregiver of the child in treatment should have a very prominent role in deciding on the types of services and supports needed because of their firsthand knowledge of the needs of their child and family. But, in reality, the team members all have a set of expertise and maybe even mandates to comply with that must go into all decisions. The goal always is to meet the unique needs of the child and family to ensure success for the child. At times this process is hindered because team members (either the primary caregiver or the providers) think that all the decision making rest on the parent/caregiver.   This leads to a frustrated team. Sometimes the provider members of the team expect a parent to know right away everything they need, how they need it and by when. Then at other times, a parent thinks they should be able to dictate to the team everything they want, the way they want it and by when. Neither of these approaches works well. The idea is that every member of the team have a voice and share responsibility while giving the parent a primary role in leading the team's decisions. Some of these challenges can be resolved through clear communication. For example:

- The team members are very clear up front about where there is flexibility and where there are mandates.
- Deciding on the type of therapeutic intervention that works best for the family can be up to the parent, but the young person seeing the probation officer once a week is not negotiable.

The team members set clear guidelines for team interactions. Everyone clearly states their needs and expectations of the team

Parents indicate that they want to choose they type of therapeutic intervention and the provider for their child and they may need the team to provide them with thorough information so that they can make an informed choice.

The same rules apply on the policy level; family members should have "a" primary leadership role on all committees, governance boards and community collaboratives where decisions are made that impact children, youth and families. This does not mean that families dictate to system leaders how to provide services, but rather families are given a primary voice and inform policy makers about what works and what needs to change to improve the systems that serve them.

What Does It Look Like?

So what does it look like and feel like when we are really implementing family-driven care? How will we know it when we see it in action?

For family members it may be a combination of any of the following:

- Families don't feel judged or blamed because of their child's behavior
- Families can ask for the services and supports they need (for themselves or for the community) and maintain a sense of dignity and respect (they don't feel patronized)
- Families are given resources and are adequately prepared for any meeting (practice level as well and policy and program level)
- Families feel valued and validated
- Families express challenges , ideas or plans and not fear alienation or retribution
- Families are not expected to have all of the answers

For providers and system leaders in may be a combination of the following:

- Policies are in place (that were developed with authentic family participation) that support family-driven care
- Families are actively involved in evaluating the service system and the decision making processes
- The voices of families are sincerely welcomed, encouraged and heard
- Resources and support are given to families in preparation for all meetings
- Systems have no reject and no eject policies when serving families (a "do whatever it takes" attitude)

- When budgets have to be cut, the family component must not be the first on the chopping block.

Keeping family-driven care in context provides the most effective way of supporting children and youth with mental health challenges and their families. Families can have a primary decision making role in the care of all children when encouraged and supported by their provider partners.

Family-Driven Policies and Procedures

Policies and procedures are necessary to the framework of all systems. These can enable the work to flow in predictable, equitable and organized fashion. Policies and procedures can also be barriers to services and to the value of family-driven practice being realized. If the family-driven value in systems of care is not clearly and explicitly articulated and mandated in the written policies of a mental health system or mental health provider agency, it will be absent in the services and supports that are provided.

For Family Members

The policies and procedures of a system or provider agency are transparent; family members have easy access to written policies and procedures and are aware of how the system operates. Access is available in the languages spoken and at reading levels that meet the needs of the community. At enrollment and on an ongoing basis, the policies and procedures are discussed, explained and reviewed. Family members and providers work in partnership to ensure family voices and choices guide decisions. Family members have responsibilities and rights that come along with embracing the family-driven definition. Families avail themselves of opportunities to become better consumers so they can be a part of driving the policy decisions in their community. They read policy materials, articles in newsletters or newspapers, talk with parent support partners, attend meetings, participate in workshops and join committees and workgroups.   Family members work to transform policies to break down barriers, stigma and disparities. Family members impact the transformation of policies and procedures by using their lived experience and expertise when completing surveys, speaking to providers and at meetings, writing letters, signing petitions and some will become leaders and represent their peers on committees and councils.

For Family Leaders and Family-Run Organizations

Family leaders and family-run organizations provide transparent system and agency policy information, advocacy and support for members, and a safe place to share their experiences and learn from each other. The leadership and members of family organizations represent the cultural and linguistic population that they serve. Outreach is purposely planned to make certain all members of the community have a place in the organization to be supported, learn and belong. Within the family organizations, all system and service information is routinely shared with all who are served. Family leaders have a responsibility to speak for all, not just for a few or only for themselves. Authentic family voice represents all, keeping confidentiality in mind. Although family organizations receive funding from provider organizations or system budgets, family leaders are responsible to keep true to family values. Policies written with this in mind will give the strongest support for the family-run organization to be effective.

Family leaders and family-run organizations are also responsible for helping to instill family voices across partnering child-serving systems. Policies and procedures requiring family participation on committees and workgroups are supported by the family organizations. The organization is the place for family leadership training and this training is essential to sustainability. Parent Support Providers are hired, trained and supervised by the family-run organization. Coaching and training of providers and their supervisors are also duties held by the family-run organization.

For Providers

Providers and their agencies are responsible for working towards transforming services and supports from provider driven to family-driven. Providers fully understand and buy into the philosophy of family-driven. This buy-in is necessary to achieve authentic family-driven participation. When system transformation begins, providers have a role in initiating policy change from provider driven to family-driven.

Providers listen to family members, ask them for feedback about what works or barriers that exist. Providers speak about families as people (not cases) and believe that families have expertise that can successfully inform policies and practices.   Providers and their supervisors actively learn how to partner with families and embrace the concept of shared decision making. This is a written policy that providers and families can write together, and provides key steps for every provider. One of the first changes may be having all agency trainings open to family members. When families and providers learn together, all know what is required, how services operate and what each can expect from the other. As family leadership is developed, family members become co-presenters with providers.

Providers are responsible to learn about the culture and values of the families they serve. Researching, attending community events and participating in cultural training are ways providers show their interest in engagement with families. Asking families about their cultural practices is another way they learn. Family culture and language are key considerations when choosing services, supports and providers.

For Systems and System Leaders

Authentic family participation at the system level is required to set the stage for overall system change. Planning and supporting a policy requiring partnership training in shared decision making for all staff and families is a starting point. Transformation at the system level begins with evaluation and re-writing of policies and procedures to require family access and participation in all decision making. In a family-driven system, the system leaders are responsible to see that families are involved in governance, all committees and workgroups. They initiate and take responsibility for recruitment and orientation of family members regarding policies and procedures, system development, providing documents and training. Families have access to the budget and vote on items to be included. Policy, including budgeting, is written to require system support for the family organizations and the work they provide. This

includes providing time, staff, training, resources and support. Family leaders who participate in writing, implementing and evaluating policy are compensated for their time and expertise.

System leadership includes family members who represent family organizations and who are members of the staff. Experience as a family member is a preferred attribute of all employees. Meetings do not occur without authentic family participation. For this to occur, meetings are scheduled at times families can attend, processes and procedures are transparent and families are invited to all training events as regular practice; family-driven scheduling, transparency and training are business as usual. When a Request For Applications is issued, the system family-driven policies are required to be included for funding consideration.

Impact

Transformed systems, those who have been successful at changing policies and programs to be family-driven, have found that families provide unique and valuable perspectives that are based on experiences and expertise. Families have ideas about why the system works or fails to work. Their reactions to established policies and proposed policies shed light on why things do not work and what changes may improve outcomes. Sharing information about and partnering with families in updating policies provides opportunities for families to impact outcomes. It also allows families and providers to share the responsibility for achieving transformative policies. Effective family leaders and family organizations ensure that the voices, needs and ideas of local families are part of all the decisions made about policies and procedures. When policies are family-driven, the system works for those it is meant to serve.

Family Driven On the Program and Practice Levels

Children's mental health programs include clinical services, peer and community supports, training, and education about mental health and the challenges some children and families experience. Family-driven practices on the program level are evident when family, family leaders, providers and system leaders partner and collaborate in planning, implementation and evaluation of all programs.

For Families

Families participate at the program level by communicating with their providers about challenges, needs, successes in accessing services and partnering with providers in development and implementation of services and supports. Families communicate with the family-run organization and parent support partners. Families also take advantage of trainings and resources in order to fully participate in services, committees and decision making events. Family members participate in evaluation of programs because they know their voice impacts system change and development.

For Family Leaders/ Family-run Organizations

The family-run organization is an equal partner with agencies in the community. Family leaders are involved in developing agency and system goals and choosing supports that will meet the needs of families to be served. At the program level family leaders and organizations represent the families being served. The organization recruits and trains family members to work in provider networks providing family support services. Peer support is provided by Certified Parent Support Providers and easily accessed by families who request that service. Families who attend system, agency and community meetings are supported by family leaders. This includes preparation for the content and process of the meeting, support during the meeting and providing time to debrief. Family members receive training on evaluation and participate as members of the evaluation team.

For Providers

Providers have an important role in developing and sustaining family-driven practices. Providers and their agencies are committed to putting family-driven practices into operation. They support family-run organizations financially and are allies in decision making, planning and implementation of practices. Experience raising a child with mental health challenges is considered an asset when family members seek employment as providers or in other agency roles. Providers partner with family leaders in their practices and embrace the role of parent support partners.

Agencies are welcoming to families and provide families with accurate and full information about practices, supports and all the possibilities for participation. Family members with lived experience

accessing mental health services for their child are employed as intake workers; they are the first contact a family will have when calling for assistance. Announcements and materials from the family-run organizations are shared. Provider agencies seek family voices and work to break down barriers. They support the understanding of practices, diagnoses and skills, so therefore they open all of their trainings and events to families. Agencies actively work to overcome stigma in their communities.

For Systems and System Leaders

Systems and system leaders are champions of family voices; they have the chief responsibility in the development of family-driven practices. System leaders embrace and practice family-driven principles in all they do. They ensure family leaders authentically represent families on every board, committee and in every plan. Family leaders are free to express the frustrations and challenges, as well as the satisfactions that families have experienced.

The system acknowledges the stigma, discrimination and barriers a mental health challenge elicits. It is seen actively and purposefully educating the community about mental health and combating the ignorance and misconceptions about mental health challenges.   At the system level, family members who have experience accessing services and supports are voting members of the boards committees and councils. The families on these boards are fully compensated for the time involved in full participation. The system advertises all job opportunities in places and ways that will attract family members to apply. Family members are included in hiring decisions and are presenters at orientations, as well as ongoing training of staff.

Impact

Systems' and provider agencies' programs exist to serve families. When families are equal partners they are more invested in the success of those programs and feel more connected to the systems. Shared work makes each step authentically valuable to all. Families know what works and what does not work for them.

Culturally Competent / Responsive Family-Driven Practice

Family-driven care as a value is meant to be all inclusive; however, as a practice it sits firmly in a Eurocentric construct. This construct can be problematic for many families because it is based upon the dominant cultures' norms. These challenges are not exclusive to people of color but to people with wide ranging cultural differences. As we plan and implement transformational practice we evolve to truly meet the needs of ALL families in the manner intended by the value of **family-driven care.**

As we continue to evolve to more transformational leadership we must also look at the concept of power in family-driven practice. Often times, there is a power differential between providers and families being served. This differential also exists when the provider is a family member. Families can feel beholden to their provider based upon the services that they are receiving or the relationship they have with the family member/provider Family leaders can sometimes be unaware of how the power that they possess is perceived through the eyes of the family. It becomes critically important that family leaders remain keenly aware of this power and how it can affect the relationship between them and the families they serve.

As family leaders we often serve dual roles of "family member" and "provider". Though we may see ourselves as family members "first and always" many times this is not how others may see us. When making decisions and sitting at tables it is important to access which role the others at the table see us in? The role that each member at the table is seen in has a direct impact of the balance of power.

For policy makers this means reviewing policies that restrict families from operating in a manner that is natural to them. We have system policies that dictate the degree of relative (1st cousin vs. 2nd cousin, aunt vs. great aunt) that can care for/have guardianship over children. For many families these distinctions are not naturally made and many times not part of the family's normal mode of functioning. For many families a cousin is a cousin and many "aunties" "uncles" and "cousins" are not blood relations but are the closest people in relationship to a child and family. Some families make all decisions collectively, or defer to a matriarch or patriarch. There have been many situations where these beliefs and practices were looked upon as illegitimate and therefore not allowed. The following is an example of how policies can restrict families from operating in ways natural to them.

A social worker comes to a home of a grandmother who is raising six grandchildren ages 4-10. Upon entering the home the social worker realizes that all six children share one bedroom with three sets of bunk beds. The social worker proceeds to tell the grandmother that regulations state that each child must have a certain amount of space and that the current arrangement is unacceptable. She then says to the grandmother "I understand that you are doing the best you can and can't afford bigger space." The grandmother replies, "the children are all in the same room because in our family children have always shared one room. It helps them be closer and learn to share". "I have other rooms, this is their bedroom". The social worker replied "these are the rules, if you want to keep the children you have to do something different".

When working with families it is incumbent on the provider to withhold judgment of a family's customs, traditions, and practices. Many times the power differential that exists between the provider and the family (even in the case of a family support provider) can create tension when the provider and the family have different belief systems. There have been situations where families have been ordered/mandated to engage in a particular action that may be seen or interpreted as a direct violation of a cultural norm. Because of the inequitable balance of power that exists in the situation the family sometimes finds themselves in a fear ridden quandary. Do you do as systems and providers tell you to do and violate your values (in front of your child that you are trying to teach the same values)? Or do you speak out and be labeled "resistant" or worse face the threat of disciplinary action against you or your child. The following are examples of how this can occur:

Example One

A devoutly religious family was in care and had regular meetings with care coordination staff. When the group came together the father did not shake the hands of the female staff. Staff recorded in the notes that the father was "standoffish" "resistant" and "non-compliant." After a number of meetings the father questioned the process and indicated that he felt that he wasn't being heard and his family customs weren't being honored. The female staff said that she felt "disrespected" and reported the father's behavior as "hostile." When questioned by a supervisor about this characterization the staff recounted the previous behavior of the father. The supervisor spoke with the father who indicated that according to religious custom men were not allowed to shake the hands of women. He also said he sensed something "off" about the interactions with staff but didn't say anything out of fear of losing the services their child needed.

Example Two

A family where a boy was being raised by a mother, grandmother and lived with two sisters requested a male service provider to support and mentor the young man. The family said that the son needed positive male influence in his life since he was surrounded by all females. The male provider conducted a few sessions of in home therapy and suggested to the mother that she needed to get the son in church and have him and the family prayed over because the family was having so much trouble due to the divorce of the parents and divorce being a sin before God . The provider assumed that because they were of the same racial group that they had the same spiritual beliefs.

Example Three

A family member is ordered into a counseling program as a provision of retaining custody of the children. In the counseling group, the leader asks participants to share how their lives are affected by substances. The family member says that their family "has been hurt and negatively impacted by drugs and alcohol."

At the end of the group the leader says in the evaluation that the family member did not complete the requirements of the program. When the family member asked what part of the program they failed to complete they were told that they did not share. The family member recounted the group meeting where they shared and was told "You didn't share correctly. You must share specific details of your experience." The family member then indicated that in their culture one does not share such details with strangers. Only family members, healers, and other trusted ones. The group leader then said "You want to keep your kids, you do this our way!"

As providers we must be the bridge for families so that they trust us to broker relationships between them and the systems that can meet their needs while allowing the families to retain their integrity, pride, and culture to remain intact and strong.

In honoring families as they are, we do our greatest work. We create wellness. We empower families to seek out their traditional ways of healing and maintaining wellness. We create safe space for families to say "we can do this ourselves" we create the opportunity for true healing and wellness. When we embrace shared decision making on all levels we create equity among all the players and ultimately set the stage for better outcomes for children and families.

Conclusion

Family-driven, both as a value and as a practice, has experienced (and is continuing to experience) an incredible evolution. As the movement has gone from families being blamed for their child's mental health disabilities to Jane Knitzer's release of *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services* to the establishment of the National Federation of Families for Children's Mental Health to the national certification of Parent Support Providers (CPSPs), we have seen families reclaim their voice. As a step to support this evolution, in this document we provided clarity on the nuts and bolts of what "family-driven practice "is, highlighted the attributes and characteristics of family-driven practice at the program and policy levels, and provided examples illustrating how to implement family-driven practices and how communities work toward being family-driven. We have provided the basic scaffolding for future learning and growth. We as practitioners must continue to evolve and sharpen our skills in delivering family-driven care as we seek to transform systems and services for children with mental health challenges and their families.

Appendix A

This appendix offers an in-depth explanation of transactional and transformational leadership in family-driven practice.

TRANSACTIONAL PRACTICE

Transactional practice is primarily defined by the nature of the relationship between the leader (provider of service) and the follower (family), which is based on "transactions" or contingent rewards. The bond built between the provider and the family is established and built on exchange; for example, providing assistance or incentives in exchange for attendance at an event or meeting.

Another characteristic is practice by exception, which describes whether leaders act to either prevent (active practice) or resolve (passive practice) problems as they arise (Lai, 2011). An individual who follows passive practice doesn't deal with or intervene in problems until they become serious. People who follow active practice gives their full exclusive attention to dealing with problems.

Transactional practice does not foster a shared vision between the provider and the family. Each partner in the relationship is motivated by the reward for the interaction. For the provider, it can be obtaining numbers to show "active family involvement." For families, it can be getting gift cards, stipends, or even an opportunity to be away from the children. These rewards are not always sustainable and can create a false sense of partnership between the provider and the family. The incentive goes away and so does the partnership.

TRANSFORMATIONAL PRACTICE

Transformational leadership represents a leadership style that is exemplified by charisma and shared vision between leaders and followers (Burns, 2010). From the perspective of family-driven practice, the power comes from a provider's ability to stimulate and inspire families to reach for goals, celebrate them as they achieve the goals, and encourage free and creative thought as they reimagine their family or the system as a whole. It involves families (and family leaders) encouraging provider partners to embrace shared decision making, supporting them in out-of-the-box thinking, and redefining the provider-family partnership. Transformational leadership has five dimensions: (1) attributed idealized influence; (2) behavioral idealized influence; (3) inspirational motivation; (4) intellectual stimulation; and (5) individual consideration. Each plays an important role.

- **Attributed idealized influence** describes the manner in which leaders (provider, family leader) are good role models. In this style, the measure of being a good role model is based on traits that are assigned to leaders by others.

- **Behavioral idealized influence** is similar to attributed idealized influence except that the measure is based on what the leaders (provider, family leader) do in their own practice (behavior). Do they "walk the talk"?

- **Inspirational motivation** describes the ability of leaders (providers) to be champions for and on behalf of their families. This speaks to the ability to keep families motivated through optimism, enthusiasm, and a sense of hope. They help the group keep "their eyes on the prize." This also happens when family leaders/members act as champions for providers who are embracing shared decision making and family-driven practice.

- **Intellectual stimulation** describes how leaders (provider, family leader, family member) are able to stimulate creativity and new ideas among the team (providers, family leaders, family members). Out-of-the-box and innovative thinking is welcomed, encouraged, and nurtured.

- **Individual consideration** describes the vested interest of leaders in the personal development of individual family members. They may serve as mentors or coaches. The use of one-to-one interactions and equitable active communication is central to this dimension.

The key in each of these dimensions is that everyone (providers, family leaders, families) has a role to play. In transformational leadership practice, the concept of working with a shared vision and goals and having all members feel valued as a part of a bigger whole is critical.

How Do We Do It? What Does It Look Like?

As providers of service to families, it is incumbent on us to constantly reexamine our practice. As we speak about not doing "to and for" families, we must constantly work to make sure that we share power and help families from the perspective of the "Guide on the Side" rather than the "Sage on the Stage." For example, on the policy level it may mean asking ourselves some of the following questions:

- Whose idea is this?

- How vocal were families during the discussion?

- Is what the families said REALLY represented in…?

- Did I give the families everything they need to actively engage in…?

- Was there balance (equity) in the (meeting, forum, etc.?)

- Did I champion the voices of families in that meeting?

- Did I offer support to the ideas expressed by families at…?

Transformational practice at the policy level also includes being the steadfast, consistent voice for families at every table at which we sit. We are working for a day when families are present at every table. Until we achieve that, and even after, it is of paramount importance that the voices for family-driven care be echoed by multiple voices across the system.

On the practice level, it also involves being that role model for families both in times of triumph and in times of struggle. Connecting with families through our own experiences throughout our journey

provides possibly the best example for families as they reimagine their lives and enhance their vision of themselves. Many families we come in contact with struggle with finding their voice as they battle with internal messages that say that their voice doesn't count for a number of reasons including but certainly not limited to these factors:

- Education or lack thereof

- Socio-economic status

- Language

- Prior behavior

- Race/ethnicity

- Gender

- Class

- Geographic location

It is part of our work as leaders to counter these negative messages through consistent motivation and support. This doesn't mean that we overlook the stumbles and challenges that inevitably come up. Instead, we work with our families to not be defined by the challenges, but rather to see them as points along their journey that they can use at a later time to help themselves and others grow. We celebrate even the small successes and encourage families to stretch themselves as they experience those successes. We gently but firmly push them to try new things.

The Impact

Transformational practice has great multilevel and reciprocal benefit. Families can become empowered by enhancing their vision of themselves and other families like them. This can lead to strong, consistent, and fully engaged family voices. Providers benefit by having fully engaged partners in planning both on the practice and on the organizational levels. Systems benefit from having a strong, sustainable family voice to guide them as policy is crafted. Constant critical analysis of our behavior as providers will yield great benefits for both us and the families we serve.

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