

# Family-Driven Care in America: More Than a Good Idea

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## Abstract

**Objectives:** This paper will provide a history of how family-driven care has evolved in the United States. **Methods:** Several examples of family-driven care including the National Policy Academy led by the Federation of Families for Children's Mental Health, the Jefferson County Kentucky's Parent Advocacy Program, and the Family Ties Resource Centers in Westchester, New York, and the 2009 American Academy of Child and Adolescent Psychiatry's Policy Statement are used to illustrate the development of family-driven care. **Results:** In the past twenty-five years the mental health field has shifted from viewing parents as the cause of their child's issues to active participants in treatment and active participants in policy development and system reform efforts. Research shows that better outcomes are achieved when family members and youth have meaningful roles in their treatment. **Conclusions:** Family-driven care has advanced in the child and youth mental health system in America and next steps are needed to further develop the ability of families to become true partners in treatment planning, service and system development, enhance research as to the effectiveness of these activities and reform policies and practices to reflect needs of families.

**Key words:** *parents, systems, reforms, family-driven*

## Résumé

**Objectif:** Présenter un historique sur l'évolution des soins axés sur la famille aux États-Unis. **Méthodologie:** Plusieurs organismes, comme la *National Policy Academy* dirigée par la *Federation of Families for Children's Mental Health*, le Jefferson County Kentucky's Parent Advocacy Program, et les Family Ties Resource Centers de Westchester, New York, et la déclaration 2009 de la politique de l'*American Academy of Child and Adolescent Psychiatry's Policy Statement* qui axent les soins sur la famille illustrent l'évolution de cette pratique. **Résultats:** La santé mentale a évolué au cours des vingt-cinq dernières années: les parents ne sont plus considérés comme étant à l'origine des difficultés de leurs enfants, mais comme des participants à part entière du traitement de ces derniers, qui interviennent dans les décisions politiques et les projets de réforme du système. Les travaux de recherche montrent que les résultats sont meilleurs lorsque les membres de la famille et les adolescents jouent un rôle dans le traitement. **Conclusion:** Les soins axés sur la famille ont progressé; il convient d'adopter des mesures qui permettront aux familles de devenir de véritables partenaires du plan de traitement; leur participation permettra de faire évoluer les services et le système; de faire progresser la recherche sur l'efficacité de cette pratique; de réformer les politiques et les pratiques afin que celles-ci tiennent compte des besoins des familles.

**Mots clés:** *parents, système de santé, réformes, soins axés sur la famille*

## Introduction

Family engagement in child and adolescent psychiatry can enhance the success of children and adolescents with mental health challenges and their families (Morrissey-Kane & Prinz, 1999; Wehmeyer & Palmer, 2003). The paradigm shift of viewing parents as the source of the problems to active partners in treatment has taken over two decades. The impact of this shift in thinking and acting has changed clinical work in communities

across the U.S. As this shift occurs, parents are beginning to feel empowered as they engage in all levels of the children's mental health care system. Historically, in the United States voices for families raising children with serious emotional and behavioral challenges were often silent before the family movement. Many families felt blamed for their child's mental health disabilities and families coined the phrase "blame and shame" to articulate how they felt. Families, however, have moved beyond labels and linear models of causation. They have created a movement that

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has evolved over the past twenty years to ensure that children with serious mental health challenges and their families are no longer identified as the problem but rather seen as partners in the solution.

## History of the Family Movement in Children's Mental Health in America

The notion that parents are responsible for a child's mental illness was the experience of parents and historically entrenched in professional thinking in the mental health field. This is evidenced by current theories that people with schizophrenia have caretakers who frequently use unclear communication styles that cause a disruption in attention (Kymalainen, & Weisman de Mamani, 2008). Likewise, a 2001 sociology text states "There is solid scientific evidence for what our grandparents always believed: parents are to blame when their children misbehave (Stark, 2001)."

The parental feel of blame could be understood within the theoretical framework of behaviorism. During the 1970's and 80's "radical" behaviorism received a prominent status within psychology. This approach posited that the environment accounted for all human behavior (Skinner, 1974). As such, a child's behavior and emotional status, for better or for worse, were the result of care giving. Thus, if a child had behavior problems, the only explanation was parental failure.

Of course this view did not take into account internal characteristics (genetics) or the broader environmental context. In 1982 the publication of *Unclaimed Children: the Failure of Public Responsibility to Children and Adolescents in Need of Mental Health* (Knitzer, 1982) drew attention to the plight of children and youth with mental health issues and posited that families needed to be considered a part of the solution rather than identified as the source of the problem. In 1986, the Research and Training Center at Portland State University, answered the call issued by Dr. Knitzer and convened the first of several conferences titled *Families as Allies*. These conferences promoted families and professionals working in collaboration. With families having access to one another and to professionals who supported them, the need for a national entity to represent family voices in system reform grew so that families could have better access to one another and to the professionals that support them.. Several small local support groups of families had already formed around the country, and in 1989, the National Federation of Families for Children's Mental Health was formed as the first national advocacy organization focused exclusively on the mental health needs of children and youth. By 2010, The Federation had more than 100 local chapters and State organizations.

National Federation advocacy assisted in the 1990 establishment the of federal Statewide Family Networks program. These networks provide information and support to families of children and youth with mental health needs and the current federal budget is over \$2 million for 48 States.

Perhaps the best example of the evolution toward family-driven care can be found in the federal Substance Abuse and Mental Health Services Administration (SAMHSA) support for the largest children's mental health initiative ever undertaken in the U.S. This initiative, called the Comprehensive Community Mental Health Services for Children and their Families Program, began in 1993 with a \$4.9 million investment. As of fiscal year 2010, the investment has reached over \$121 million per year and has provided services in 164 localities. This program presents a youth-guided and family-driven approach to service delivery and the agency has worked to strengthen the influence of families every year (Stroul & Blau, 2008).

## Defining Family-Driven Care in America

An important milestone in the evolution of family-driven care was the creation of the New Freedom Commission on Mental Health by George W. Bush in 2002. This commission was charged with the study of the mental health delivery system in America with the goal of making recommendations that would, among other things, enable children with serious emotional disturbance to live, work, and participate fully in their communities. The National Federation's Board President and family member, Jane Adams, was appointed to the Commission, thus adding the voice of families with lived experience raising children with a serious mental health challenge.

In 2003, the Commission produced a final report entitled *Achieving the Promise: Transforming Mental Health Care in America* (NFC, 2003). This report identified six goals as the foundation for transforming mental health care in America. Goal two of the report stated "In a transformed Mental Health System, mental health care must be consumer and family driven (NFC, 2003)."

In 2004, The Substance Abuse Mental Health Services Administration (SAMHSA) asked the National Federation of Families for Children's Mental Health to develop a definition of "family-driven care." An expert panel, consisting of family leaders and other professionals, was formed to develop the first draft of a definition of family-driven care. This working definition states that "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. This includes: choosing culturally and linguistically competent supports, services, and providers; setting goals; designing, implementing and evaluating programs; monitoring outcomes; and partnering in funding decisions (Osher, Osher, & Blau, 2008)" This definition is used across the country and continues to be refined.

The National Federation of Families developed a training curriculum called "On the Road to Family Driven Care." This training was developed as a tool to help individuals, communities, and systems value family engagement in services and systems ([www.ffcmh.org](http://www.ffcmh.org)).

## Making the case for Family Engagement: Research Evidence

Research evidence demonstrates that outcomes improve when family and youth are active participants in their own treatment (Morrissey-Kane & Prinz, 1999; Wehmeyer & Palmer, 2003). Furthermore, commitment to treatment increases when youth and families are given leadership roles in making their own clinical decisions (Manteuffel, 2010). The evidence base for family involvement in mental health care is influenced by many disciplines including early childhood development, education, mental health, physical health, child welfare, and juvenile justice to name a few. Family involvement is critical to improving school outcomes, mental health outcomes, and reducing mental health disparities (Osher, Osher, & Blau, 2008). Osher, et al., (2008) described two threads of rationale for parental involvement in mental health care. The first is that “parents have special knowledge that can enhance the design of interventions and treatments (Osher et al., 2008, 47).” Parents frequently have more intimate contact with their children than mental health care professionals and as a result they can help with observations of symptoms and treatment efficacy. Parents also share cultural knowledge with their children, making their input critical in contextualizing interventions (American Academy of Pediatrics Committee on Hospital Care, 2003). Hence, parents may be the best resource for designing, adapting, and monitoring culturally appropriate interventions.

The second point offered by Osher et al. (2008) is that “parents can promote healthy development, can prevent problems from developing or exacerbating, and can implement effective treatment protocols and educational interventions (p. 47).” Families are often the most immediate context of child development, giving parents the ability to promote healthy development and reduce or eliminate risk factors. Parents also have frequent contact with their children, making it possible to implement and reinforce a child’s established treatment plan. Research has shown that parents are more likely to support a treatment plan that they feel is effective (Spoth & Redmond, 1993, 1995; Spoth, Redmond, & Shin, 2000). Parental involvement in interventions is dependent on many factors. These include knowledge about the intervention, openness to suggestions about behavior change, and comprehension and retention of these suggestions (Osher et al., 2008). The relationship the professional forms with the parents is also critical in that it can impact parents’ adherence to preventive and treatment activities (Prinz et al., 2001).

## Family Support Programs

Family support services delivered by peers have been an important component in the children’s mental health field for 25 years. Hoagwood et al. (2009) defined family support services as “meeting the needs of parents or caregivers of children with mental health needs with the explicit purpose of helping parents/caregivers (a) clarify their own needs or concerns; (b) reduce their

sense of isolation, stress, or self-blame (c) provide education or information; (d) teach skills; and (e) empower and activate them so that they can more effectively address the needs of the family (p.3).” These services have recently become reimbursable service in some States and are frequently delivered by parents of children with diagnosed mental health disorders. The range of family support services often includes emotional support, psychoeducation, and advocacy (National Federation of Families for Children’s Mental Health (NFFCMH), www.ffcmh.org, 2008). Peer family support advisors are often able to build trust with family members due to their own personal experience (Osher et al., 2008). This peer support can help the parent become better involved in their child’s care and because of this, the number of professional peer family advisors is on the rise. Family organizations such as NFFCMH continue to promote this growth and are currently developing a credentialing system for these professionals.

## Examples from the Field: From Policy to Practice

### ***The National Policy Academy: Families take the Lead***

The National Federation supported by SAMHSA ran the first ever Family-Driven Policy Academy in 2009 where six States (Arizona, Colorado, Illinois, Michigan, New Hampshire and Tennessee) met to formulate an action plan to transform the children’s mental health delivery system (**Table 1**). The Policy Academy provided a venue for States to develop public policies to address Goal Two (that mental health should be consumer and family driven) of the President’s New Freedom Commission on Mental Health (NFC, 2003).

Following the Policy Academy, the six States went on to implement their action plans with positive results. Below are some examples demonstrating the impact of this family lead policy academy.

Colorado’s core group of Policy Academy participants crafted language to amend an existing statute concerning family advocacy to better define who can function as a family advocate. In addition, the group is exploring ways to credential/certify family advocates so that their services can become Medicaid-reimbursable.

Tennessee collaborated with their statewide network to change the language in systems of care programs from “family involved” to “family-driven.” In addition, the Medicaid Division has included this language in all contracts for Medicaid Services.

### ***Doing Real Work in States: Kentucky and New York***

Although broad implementation of the principles of family-driven care remains in its infancy, some communities have developed exemplary programs that fully embrace these

**Table 1 Policy academy objectives**

Define concrete objectives for a family-driven policy initiative that relates to Goal 2 of <i>Achieving the Promise</i> , the report from the New Freedom Commission
Determine the type of policy strategy (e.g., legislation, an executive order, or memorandum of understanding) that will accomplish its objectives.
Strategize the next steps for gaining the political will required to support and move the proposed family driven initiative through the governmental processes.
Begin to plan and design the family-driven policy initiative and to develop an ongoing implementation plan.
Form strategic partnerships to facilitate the successful implementation of the policy initiative.
Plan how to evaluate the effect of the policy on practice.

principles. Two such programs are Kentucky's Parent Advocacy Program in Jefferson County, and Family Ties Resource Centers in Westchester, New York.

The Parent Advocacy Program in Jefferson County, Kentucky, established in 2004, is an example of an initiative that has successfully navigated the challenges of implementing family-driven care. This program selects and trains parents, who were previously recipients of child-welfare services, to be peer advocates to parents whose children are currently being served by the child-welfare system. Parent Advocates and child welfare staff work together to prevent the removal of children from their homes, reunify children with their families appropriately, maintain connections between parents and children who are in out-of-home care, and help train workers and foster parents on the needs of birth parents.

A second example of a successful family-driven care initiative is Westchester County, New York's Family Ties Resource Centers. Family Ties of Westchester established itself as an independent not-for-profit organization in 2002 and is a grassroots organization providing advocacy and support services to families. Family Ties offers support groups, training in parenting skills, advocacy efforts, and respite opportunities at its seven Resource Centers. Family Ties recognizes parents as full partners in planning for their children's treatment and services and helps empower parents to participate in the decision-making process ([www.familytieswestchester.org](http://www.familytieswestchester.org)).

A key factor in the success of these two programs is the peer support. Helpers with similar experiences are often more acceptable to families than helpers who may be perceived as having different experiences, situations, social status, or an authority role (Cohen & Canan, 2006). A review of these two programs highlights the key characteristics that are necessary for the successful implementation of family-driven care approach. These include organizational readiness, training, and professional development for families. The first is organizational readiness and training and professional development for families. As family members make

the transition from clients to partners and leaders in system change, they require an understanding of the child-serving system and its legal mandates. Training and leadership development help family partners acquire the skills necessary for system change and establish a foundation for sustained involvement and success.

### ***American Academy of Child and Adolescent Psychiatry Policy Statement***

The American Academy of Child and Adolescent Psychiatry developed a policy mandating that youth and families have a primary role in their treatment and decisions made regarding their treatment. This was preceded by a mandate by the Institute of Medicine that health care should be customized to account for individualized needs and values where the patient is primarily in control of treatment (Institute of Medicine, 2001). AACAP acknowledges the value in the different knowledge, values, beliefs, life experiences, and skill sets that families, youth, and treatment professionals bring to a treatment team (American Academy of Child & Adolescent Psychiatry, 2009). It is in the best interest of the youth for all members of the team to show a mutual respect for others and value the differing perspectives. AACAP calls for youth and family involvement at every step of the treatment process from initial intake/assessment to outcome evaluation. Additionally, families and youth must be involved in decision making at the federal policy and systems levels. This policy is consistent with the Federal policy on youth and family involvement.

### **Conclusion and Next Steps to Realize Authentic Family-Driven Care**

Despite advances in the involvement of families as authentic participants in the field of children's mental health, more work is needed. It is now time for the "next frontier" of activity. This involves further development of the ability for families to become true partners in treatment planning, service and system development, and paid providers of care. The Building Bridges

Initiative ([www.buildingbridges4youth.org](http://www.buildingbridges4youth.org)) is one successful model of these principles. This initiative proposed including a Child and Family Team (CFT) in all residential treatment. This team is defined as “a group of people chosen with the family and connected to them through natural, community, and formal support relationships who develop and implement the family’s plan, address the unmet need and work toward the family’s vision” (Miles et al., 2006, p. 9). Moreover, research supports the value of the CFT in improving outcomes across domains (Blau et al., in press).

The next frontier also involves increasing research efforts on the effectiveness of these activities and the refinement of policy and practice. With one in five young people in America experiencing a mental health problem, there’s no question that everyone is impacted. The field of children’s mental health needs leaders and champions to advance to the next frontier; leaders and champions from all disciplines, but most especially from the psychiatric community.

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The authors have no financial relationships or conflicts to disclose.

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