Family Involvement in Child-Serving Systems and the Need for Cross-Systems Collaboration

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Introduction

In March 2009, the Substance Abuse and Mental Health Services Administration (SAMHSA) released an issue brief, Family Involvement in Adolescent Substance Abuse Treatment. Written by family members and professionals, the brief focused on parent-professional partnerships in the adolescent substance abuse prevention, treatment, and recovery system. Specifically, it looked at family involvement within practice, program, and policy domains. Among the conclusions articulated in that brief was that “the family voice in adolescent substance abuse is becoming stronger.”

Prior to the release of this first issue brief, there was no national family voice within the adolescent substance abuse system. Since then, a number of important events have occurred. In 2009 SAMHSA convened a meeting entitled Families of Youth With Substance Use Disorders: A National Dialogue. As a result of that meeting and the recommendations in a 2010 report, a group of family members created a national networking coalition that became known as the National Family Dialogue for Youth With Substance Use Disorders (NFD). NFD began to address the needs articulated in the report, which included outreach to families across the nation who were experiencing or had experienced adolescent substance abuse. In the process of conducting this outreach, NFD identified an emerging theme: many families involved in the adolescent substance abuse system are also involved in other child-serving systems.

This second issue brief, written by two family members who serve as codirectors of NFD, reviews what has been accomplished to date in the development of the family voice in all the child-serving systems—not just the substance abuse system but also the systems of mental health, child welfare, juvenile justice, trauma support, education, and primary care. In this review, we indicate what needs to occur to create true cross-systems collaboration supporting family involvement, so that youth and their families can fully access the service and supports they need to obtain and maintain optimum health.

Data for this review were obtained through an environmental scan NFD conducted in 2010. This scan included a review of relevant reports and an informal survey of its members. Responses to the survey were obtained from 370 respondents representing 42 States and tribes. The theme NFD had identified was confirmed by the survey results: on average, respondents were involved with a minimum of three systems. More than three-quarters of the respondents were involved with more than one system, and one-quarter were involved with five or more systems. Family representation was identified across systems but varied significantly from system to system. Participating on advisory boards, providing public education, and engaging

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1 “Family involvement,” as defined in the 2009 issue brief, is “any role or activity designed to provide youth and families with direct, ongoing, and meaningful input into and influence on substance abuse system policies, programs, and practices that affect the health and wellbeing of youth and families served.” The definition is from “CCSI Family Involvement and Strengths-Based Practices” by the New York State Council on Children and Families (see Bibliography).
in peer-to-peer support were among the most prominent ways families are involved.

Exhibit 1. Involvement With Systems

Exhibit 2. Involvement With Community Activities

**Family Involvement Within Each Child-Serving System**

This section reviews the extent of a national family voice and family involvement within each of the major child-serving systems.

**Adolescent Substance Abuse**

In the NFD survey, well over half of respondents—57.3 percent—indicated that they were involved with the adolescent substance abuse system. In past decades, family involvement in this system has been minimal. Pockets of excellence existed—parent support groups, parent-led educational programs, and parent groups involved in policy work and legislative action—but no clear-cut national family leadership had emerged.

In 2004, SAMHSA introduced State Infrastructure Grants, which called on grantees to involve families in adolescent treatment efforts. This focus continued with the implementation of SAMHSA’s State Adolescent Coordination (SAC) grants; family involvement was one of the five priority areas for grantees.

This grantee work, and SAMHSA’s continued outreach to other States and tribes, led to the first national meeting of family members of adolescents with substance use disorders—the 2009 National Family Dialogue for Youth With Substance Use Disorders. Meeting participants were mainly recruited from involved families in the SAC States. NFD planners also used the snowball nomination approach to recruit participation by family leaders from non-SAC states and Native American tribes.

At this historic meeting, family members identified the need for a national organization to move the voice for family involvement to the forefront. NFD emerged to fill that role. The organization has identified family groups across the country that focus on supporting families with adolescents who have been or are involved in the substance abuse system, while encouraging family involvement (see Web Resources for links to some of these groups). NFD has also identified many individual family members who have
moved to the forefront of leadership within the adolescent substance abuse system.

An ongoing goal of NFD is to unite the family voice within the adolescent substance abuse system and to link it with other family voices across child-serving systems. NFD has developed a memorandum of understanding with the Partnership at DrugFree.org to collaborate on family engagement. NFD has also developed a brochure and conducts ongoing social media outreach. Since 2011, it has facilitated monthly educational calls among involved family members. In 2013, NFD developed a 3-year strategic plan and took the first steps toward becoming a nonprofit organization.

**Children’s Mental Health**

According to the NFD scan, more than two-thirds of respondents were involved with the mental health system—more than were involved with any other system of care. Across the country various families and groups had been advocating diligently in local and regional efforts, and in the late 1980s, the National Federation of Families emerged as a leader in bringing the family voice within the mental health system forward to the Federal level. A number of reports also have helped to bring attention to the issue of children’s mental health, including the role of families within the mental health system (see Bibliography).

Two SAMHSA programs have helped support family involvement in the children’s mental health system. The first is the agency’s Statewide Family Network Program, which is designed to “enhance state capacity and infrastructure to be more oriented to the needs of children and adolescents with serious emotional disturbances and their families.” Grantees are tasked with providing “information, referrals, and support to families who have a child with a serious emotional disturbance and create a mechanism for families to participate in State and local mental health services planning and policy development.” (The quoted language is from the SAMHSA Grant Request for Applications.) The second SAMHSA program is the Children’s Mental Health Initiative, which provides coordination among the various systems that serve children and youth from birth to age 21 diagnosed with a serious emotional disturbance; the initiative emphasizes the inclusion of families as key stakeholders.

The family voice within the mental health system has continued to grow. Nearly every State now has a Statewide Family Network that serves families of children with mental health needs. Family organizations have emerged through State, tribal, and territorial initiatives supported by public and private funds. These organizations provide a variety of services, such as parent-to-parent support, education, governance, and oversight.

**Primary Care (Physical Health)**

In the NFD scan, two-thirds of respondents reported that they had involvement with the primary care system—the part of the overall medical care system that provides physical health services. Within this system, family involvement is reflected through such avenues as patient satisfaction surveys and patient rights protections. For many diseases such as childhood cancer and cystic fibrosis, a specific family voice is also present. Many of the family involvement initiatives that have developed within this system had their genesis in responses to practices or
procedures such as immunizations, use of medications, and surgical interventions.

The distinct family voices are supported through a variety of sources. For example, Families USA deals with children’s health policy and education. This national effort is not exclusively centered on children’s health, however; its current focus is on implementation of the Affordable Care Act.

**Juvenile Justice**

Approximately one-third of responders indicated that they had involvement with the juvenile justice system. A family voice can be found within this system in various locations across the country, but until recently no clear leadership had emerged. In 2005, the Campaign for Youth Justice (CYJ) was founded by a family member whose life had been impacted by the justice system. This organization involves youth and families who have been directly affected by the juvenile justice system in advocacy efforts. Out of those efforts, CYJ formed the Alliance for Youth Justice (AYJ) to advocate for policy reform in the juvenile justice system. CYJ and AYJ both offer educational materials, tools, skill development, and leadership training, and both are attempting to become national in scope.

With input from family members across the country, in 2012 CYJ published *Families Come First: A Workbook to Transform the Juvenile Justice System by Partnering With Families*. This workbook is a comprehensive analysis of current family engagement and family partnership practices in the nation’s juvenile justice system. It provides practical tools and resources for practitioners invested in undertaking a family-driven approach to juvenile justice.

**Child Welfare**

According to the NFD survey, one-quarter of respondents reported involvement with the child welfare system. Many child welfare agencies struggle daily to engage families that have experienced, or are at risk of experiencing, abuse and neglect. Challenges are posed by high caseloads for social workers, resource limitations, and a reliance by some populations on traditional practices that have been passed down through cultures. The child welfare system is also fragmented by particular concerns, such as permanency placement, adoption, and issues related to imprisonment, poverty, and abuse or neglect.

Some family supports are woven throughout the system. These include education and parenting resources, peer-to-peer support, and specific initiatives based on family-driven principles. For example, Family Resource Centers provide education and resources in community settings including schools, housing projects, churches, libraries, and other public and private buildings. Another example is the network of Parent Partner Programs that engages parents previously involved in the child welfare system to serve as mentors to currently involved parents, providing support, advocacy, and help in navigating the system. Parent Partner Programs also use the family experience to influence changes in policy and protocol, encourage shared decisionmaking, strengthen individualized plans, and educate the community.
“Today I not only work for but also am learning about a very complex child welfare system. I am now a part of the solution. I sit on various committees where my voice is of value, and where there are administrators and directors who really want to know what it is that’s going to help change the face of child welfare.”
—Family Partner

Common Factors of Family Involvement

Within each of the child-serving systems, there is some organized family voice mobilized to advocate, inform, and improve the delivery of services. What varies by system are the degree to which the family voice is present, the way it is involved, and how it is funded. Family involvement has been able to advance more quickly within those systems in which there are longstanding mechanisms of support through consistent and varied funding streams.

In each child-serving system, the emergence of an organized national family voice has been in direct response to specific concerns of families. For example, the issues that galvanized families within the substance abuse system included access to, and availability of, effective and affordable adolescent substance abuse treatment.

Navigating each of the different child-serving systems requires experience within that system. This means that families must learn new processes, rules, and requirements for each system with which they are involved.

The persistent culture of blame and shame that families often endure creates a significant challenge to family involvement within each system. It becomes very difficult to build the level of trust needed to fully engage families. Another challenge is presented when professionals have preconceived and limited notions of what it means to involve families.

Sometimes the professionals within a child-serving system fail to recognize or treat families in culturally competent ways.

Trauma

One-quarter of respondents to the NFD survey reported involvement in the trauma treatment system. This number more than likely understates actual involvement, since most families that have experienced trauma are not aware that they have as such.

Unlike the other systems included in the NFD survey, trauma treatment is not typically recognized as a distinct child-serving system. However, it was included in the survey because of the importance of trauma-informed services to effective treatment for addiction and the pervasiveness of adverse childhood events among adolescents with substance use disorders. The National Child Traumatic Stress Network, founded in 2001, has helped to foster and facilitate a growing family voice in this arena through its Partnering with Youth and Families Collaborative Workgroup.

“If you were trauma-free before getting involved in the system, it won’t last for long. As parents we are traumatized by the system. Leaving your child at the psychiatric hospital, walking away as the door locks, or seeing your child in handcuffs—there is nothing in the world more traumatizing than these experiences.”
Systems typically limit their concern or interactions in ways that can be off-putting and culturally offensive. Furthermore, the way a system operates can inadvertently cut families off from their community, further traumatizing family members at a time when they most need that positive support.

There are common issues of concern to families that cut across all the systems. Examples include the issues of stigma, seclusion and restraint, and out-of-community placements. Core values also emerge across systems, for example, the values of providing peer-to-peer support and experienced system-specific navigators.

Several benefits result from family involvement within a child-serving system. Families are more effectively positioned to learn about current services, policies and procedures, emerging trends and challenges, and available research from professionals. Professionals have more opportunity to learn families’ unique experiences and perspectives and to identify the strengths and weakness of the services and systems. When families are engaged and enabled to take responsibilities, greater interagency communication and community collaboration takes place, quality of treatment and policies increases, and the outcomes for families improve.

**Challenges for Cross-System Family Involvement**

The organized family voices within the different child-serving systems emerged at different times and with different levels of support. They are at different stages of development and are operating with different levels of capacity. These differences impede cross-systems collaboration.

Each of the child-serving systems has differing degrees of implementation of key principles of family involvement and differing definitions of what one means when talking about family involvement. Through its Systems of Care initiative, SAMHSA has published operational definitions of “family-driven” and “child-centered” systems of care to guide the Mental Health system. However, other systems are not working with these definitions, and this presents a challenge when trying to connect across systems.

The Systems of Care initiative identified five main challenges to building meaningful family involvement: agency child-serving system partnerships, agency readiness, training and professional development for families, recruitment and retention of family members to serve as resources to other parents, and funding issues to support these efforts. These challenges are present in cross-system involvement as well.

“Four of every five children and teen arrestees in State juvenile justice systems are under the influence of alcohol or drugs while committing their crimes, test positive for drugs, are arrested for committing an alcohol or drug offense, admit having substance abuse and addiction problems, or share some combination of these characteristics, according to a report released by the National Center on Addiction and Substance Abuse (CASA) at Columbia University.”—Excerpted from the press release for Criminal Neglect: Substance Abuse, Juvenile Justice and the Children Left Behind, published by the National Center on Addiction and Substance Abuse at Columbia University (see Bibliography)
Successes in Cross-System Involvement

Some cross-systems sharing is taking place, primarily for two reasons. First, many families have gained experience and knowledge working with multiple systems. Second, major family-supporting organizations have recognized the need for cross-systems sharing and have advocated for it. For example, NFD is working to build collaborative relationships and share knowledge across systems to reach families in other systems that are experiencing substance abuse issues.

Exhibit 3. The National Family Dialogue on Well-Being for Children and Families

Recommendations

An array of strategies for collaborating across child-serving systems is necessary to achieve better outcomes for adolescents and their families. Getting to these outcomes involves change at the program, practice, and policy levels. Recommendations for integrating family involvement across systems are listed below.

- Family involvement should be the expectation in every State, tribe, and territory.
- A family-driven and youth-guided definition of family involvement that cuts across child-serving systems should be developed to create a standard of care.
- Family members should be approached in positive, noncondemning, and strength-based ways and respected for their experience, knowledge, and skill sets.
- Principles across all child-serving systems should include: meeting families where they are, respecting each family’s culture and diversity, hearing and respecting each other’s voice, building consensus, and expecting results.
- To build bridges between the child-serving systems, each family involvement voice needs to be cultivated and supported, and individual family members need to be provided with opportunities for expanded roles and increased leadership. Separate system family involvement leadership and growth are necessary to develop collaborative partnerships with equal voices.
- Families need to look at what family leadership in other systems has been doing, glean from the lessons learned, and continue to strengthen the family voice within the systems in which they find themselves.
- State and county agencies can proactively gather and use family input by including family members on agency councils and boards.
National family voice organizations within the different systems can work collaboratively on mutual issues of concern, share information and resources, and provide linkages when needed. For instance, the family needing assistance with a substance abuse issue, who has been receiving services within the children’s mental health system, should have ready access to peer-to-peer support available from families who have navigated the world of adolescent substance abuse treatment and recovery. The family who has a child involved with the juvenile justice system and is seeking information about the substance abuse issue that led to the involvement should have equal access to family support.

The strategy of families reaching out to families is essential to expanding family involvement across child-serving systems.

One possible model going forward is to create an over-arching association that links family voices throughout systems. This would facilitate information sharing, referrals, and advocacy on issues of mutual concern.

Conclusions

While NFD has made great progress in developing a family voice and advancing family involvement within the adolescent substance abuse system, outreach to families involved with other systems is critical. Our survey demonstrated that most of the families we work with are involved with multiple systems, and there needs to be an effective way for these families to navigate across systems. Each system has an individual focus; however, it does not serve families when each system has a separate approach to their involvement. The development of a family-driven and youth-guided definition of family involvement that cuts across child-serving systems would go a long way in helping to create a standard of care.

Finally, it would serve families to have a network or association to contact and obtain access to family resources within each system, so that if the need arises they have connections beyond the system with which they are experienced. Our scan tells us that for many families, this need does arise. We should consider how we are responding, so that we do not further fragment systems of care, but rather create mechanisms for full support to families wherever they are in the process of ensuring health for their adolescent family members.

Bibliography


SAMHSA Web Resources

Substance Abuse and Mental Health Services Administration (SAMHSA)
http://www.samhsa.gov

National Center on Substance Abuse and Child Welfare
http://www.ncsacw.samhsa.gov

SAMHSA Store
http://www.store.samhsa.gov

Systems of Care Core Values
http://www.samhsa.gov/children/core-values.asp
Other Web Resources

Campaign for Youth Justice
http://www.campaignforyouthjustice.org

Coordinated Children’s Services Initiative Family Involvement and Strengths-based Practices
New York State Council on Children and Families
http://ccf.ny.gov/CCSI/CCSIFamInvolv.cfm

Families USA
http://www.familiesusa.org

Family Resource Centers
Child Welfare Information Gateway
Administration for Children & Families
https://www.childwelfare.gov/preventing/programs/types/familyresource.cfm

Learn to Cope
http://www.learn2cope.org

Massachusetts Organization for Addiction Recovery
http://www.moar-recovery.org

MOMSTELL
http://www.momstell.org

National Child Traumatic Stress Network
http://www.nctsn.org

National Family Dialogue
http://www.momstell.org

National Federation of Families
http://www.ffcmh.org

Parent to Parent
http://www.p2pusa.org

Partnership at DrugFree.org
http://www.drugfree.org

Science and Management of Addictions Foundation
http://samafoundation.org

The 24 group
http://www.the24group.org

The Addict’s MOM
http://addictsmom.com

Hearts of Hope
http://theheartsofhope.org