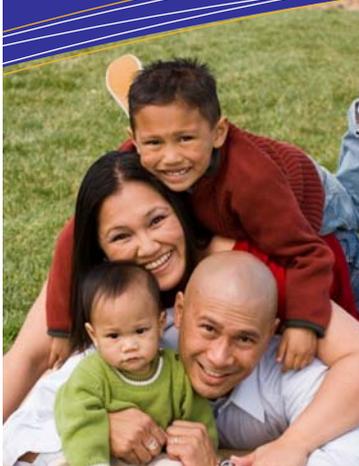


Snapshot

JANUARY 2009



Family involvement: Putting policy into practice

Strategies to develop family-driven mental health services

Consumers and families with a child with serious emotional disturbances have a key role in expanding the mental health care delivery workforce and creating a system that focuses on recovery.

- President's New Commission on Mental Health (2003)

Since 1984, when the concept of family-driven care was incorporated into national policy with the Child and Adolescent Service System Program (CASSP) principles, there has been growing demand for increased consumer and family involvement in the planning, delivery, and evaluation of mental health services. Yet 25 years later, mental health agencies, and other systems serving children, struggle to effectively put policies and principles into practice.

This snapshot highlights the benefits of involving families in mental health services. It also presents successful strategies, as well as common challenges and how service providers have addressed them.

Providing family-driven services

Successfully implementing family involvement strategies requires a shared understanding across all levels of an organization, and an openness to modify practices to incorporate the principles and values of family-driven care. Family members can be involved as board representatives, parent support group leaders, peer mentors, or agency staff.

Parent advisory representatives

Many organizations have found that including family members on advisory boards, committees, and administrative meetings can provide a valuable perspective. Family input can be very helpful in any number of decisions from hiring of new staff, to developing programs, to modifying services and strategic planning.

Providing childcare, or reimbursing parents for transportation expenses may allow more parents to serve as advisory representatives. It can also be beneficial to allow staff extra time to provide parent representatives with additional information about the program, build relationships, and respond to questions that arise.

Parent support groups

A number of organizations provide support and advocacy for children with mental health needs and their families. These groups can be hosted by the service-providing agency, or by a community-based support and advocacy group the agency has developed a relationship with. Agencies may provide space for a support group hosted by another organization.

Successful parent groups are convenient and responsive to the needs and interests of families. For example, some parents may

What is family-driven care?

In this snapshot, we use key principles developed by the Federation of Families for Children's Mental Health:

- Family and youth experiences, goals, and perceptions are used to steer decision-making in all aspects of service and system design, operation, and evaluation.
- Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued.
- Administrators and staff activity demonstrate partnership with all families and youth by sharing power, resources, authority, responsibility, and control.
- Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise when making decisions about treatment and services.

simply want to socialize and develop relationships with other families, while others may be interested in finding programs that allow their children to participate in recreational and social activities in a supervised environment. These programs can be developed and led by parent volunteers, but it may be necessary to hire an individual to coordinate activities, encourage parent participation, address barriers to participation, and respond to the changing needs of staff and families.

Peer mentoring

A number of agencies have developed programs that match parents with peer mentors who can offer assistance navigating the mental health system or provide other support or informal opportunities for parents to connect and share experiences. Although peer mentoring is often a volunteer activity, stipends and training can be offered to parents who serve as mentors. In addition, some administrative or organizational support may help the program run smoothly.

Reimbursable positions

Although funding can be a challenge, some organizations have developed ways to get reimbursed for services provided by family members and consumers.

For example, a family-run organization in Arizona provides training to parents and serves as a hiring agency for mental health and social service organizations that are interested in employing family members as staff. Two of these parent staff positions are Family Support Partners, who work with case managers and facilitate communication and relationship-building between families and case managers, and Parent Partners, who

provide direct services to families and reinforce the development of positive parenting skills.

Developing these permanent positions often requires strong coordination between local agencies, state and federal policy-makers, and family-run organizations.

Benefits of family involvement

Although there is limited research, early studies have shown that family-involvement programs help parents develop more positive feelings about their child's treatment and improve their parenting skills. Some research suggests that parent involvement can lead to shorter stays in residential placements.

There is also evidence that family involvement can improve service delivery. Family members hired as service providers often spend more time with clients, demonstrate greater sensitivity to individuals served by the agency, and help other professionals focus on recovery instead of possibilities of poor mental health outcomes.

Existing research methods that focus primarily on alleviation of mental health symptoms as evidence of program effectiveness may not fully capture the benefits of family-involvement initiatives. Similarly, traditional research approaches that emphasize the use of randomized controlled trials and fidelity to standard programming do not easily allow for flexibility and individualized services, principles that are essential to family-driven care. New research strategies and outcome measures must also be explored with families to determine better ways to examine the effectiveness of these services.

Overcoming challenges

Agencies interested in developing initiatives to increase family involvement face a number of common barriers, such as tokenism, role ambiguity, staff tension, and lack of long-term vision. Although these issues can be difficult to address, there are a number of effective strategies that agencies have used to overcome these challenges.

Tokenism

Tokenism occurs when family members are invited to be involved in an agency, but have little power. This can happen when family members and agency staff differ in their expectations of the role families have in the decision-making process. If expectations are not clearly articulated, family members are likely to feel dissatisfied.

Some strategies that can help to avoid tokenism include:

- Create meaningful positions for family members that include appropriate professional development, training, and mentoring opportunities
- Provide family members with the information and training they need to meaningfully participate in the decision-making process
- Increase the level of family involvement in the organization by designating 25 to 50 percent of board or committee membership for families
- Create opportunities for family representatives to discuss options and gather feedback from a larger group of parents and families

Role ambiguity

When family members are hired as staff, there is often a lack of clarity about their new role. They may feel conflicted about presenting themselves as a peer to other families or as part of the agency staff, especially if they are hired by an agency that has provided, or continues to provide, services to their child.

These strategies can reduce feelings of role ambiguity:

- Provide comprehensive training to all staff, including clear information about roles and responsibilities
- Develop strategies to provide ongoing supervision and/or mentoring to new staff

Staff tension

Although families and staff members often share a common goal that the child receives appropriate and effective mental health services, there can be tension over sharing of roles or decision-making power. Staff members, who are recognized and promoted because of their professional degree or licensure, may not recognize the expertise, skills, and knowledge parents have developed through their personal experiences.

Strategies to alleviate tension between staff and family members include:

- Create a shared vision among all agency staff
- Develop new policies that distribute decision-making power and authority
- Use processes that require interagency collaboration and consultation to promote communication between traditional agency staff and family members

Lack of long-term vision

Too often, family-involvement initiatives are funded by short-term grants instead of sustainable funding sources. An agency developing a new family-involvement initiative should consider the following questions:

- How does this initiative fit with our agency's mission and values?
- How will we recruit family members to employ at our agency?
- What types of information, training, or professional development activities will we need to offer? How does this fit with our training and educational reimbursement policies?
- How much decision-making power will family members have?
- How will we change our decision-making process to fully involve family members?
- How will we support these positions and/or develop long-term funding to support new positions?





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Getting started

An effective way to assess the degree of family involvement in an agency is by using a collaborative approach led by a group of key stakeholders—parents, program staff, and agency administrators—to identify key questions to examine current agency policies, assess the needs of parents and families, consider opportunities to develop new services and supports, and seek funding.

Some of the key questions to consider include:

- Does your agency have an explicit policy on family participation in planning, decision-making, and service provision? Is it written down? Are staff and families aware of it?
- How many family members are board members? Are they voting members? How do you recruit family members to serve on the board?
- What accommodations do you provide to help families participate in meetings?
- When recruiting new staff, do you advertise in a way that attracts family members? Do family members hired as staff have the same roles and access to information as non-family member staff?
- Do you regularly solicit family input into service planning and provision? Is this input likely to alter service provision and practices?
- Are family members involved in hiring decisions? Are family members involved in evaluating agency services?
- Do you invite family members to participate in agency training events? Do family members participate in training and orienting new staff?

-Adapted from the Centre for Community Change through Housing and Support, Trinity College (Burlington, VT)

Additional resources

Duchnowski, A. J., & Kutash, K. (2007). *Family-driven care*. Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Department of Child and Family Studies.

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