



PRACTICING RECOVERY: Family Engagement

The Importance of Family in Recovery

Family engagement and involvement in health care decision-making and treatment can be a key to recovery for individuals diagnosed with a serious mental illness. When practitioners, people in recovery, and their families work collaboratively, clinical [outcomes](#) and quality of life often improve. Access and engagement are foci of the new federal Interdepartmental Serious Mental Illness Coordinating Committee’s (ISMICC) recommendations in their November 2017 report, [The Way Forward: Federal Action for a System That Works for All People Living with SMI and SED and Their Families and Caregivers](#). Often, successful family engagement is built on cultural sensitivity, understanding of family relationships, and a flexible idea of what constitutes a family.

This issue of *Practicing Recovery* provides information on family engagement, including an overview of the importance of culture in families, tips from an innovative family-led program that focuses on empowering parents, and resources where you can learn more. Readers will also find tools for incorporating this important information into practice.

To learn more, see the following resources.

National Alliance on Mental Illness (NAMI)

NAMI is the nation’s largest consumer- and family-focused mental health organization. [NAMI](#) offers education, advocacy, and leadership around mental illness. NAMI has hundreds of local chapters across the United States that offer a range of training and services. NAMI has a crisis helpline, blogs, and other educational materials, and it hosts an annual national meeting.

SAMHSA’s Family Psychoeducation Evidence-based Practices KIT

This five-module digital [workbook](#) is designed to help practitioners learn about the principles, processes, and skills necessary to deliver effective family psychoeducation services. This toolkit includes information on the basic elements of family psychoeducation, how to incorporate it into practice, how to hold information and education workshops, family psychoeducation support groups, and real-world solutions to problems that come up in practice.

U.S. Department of Veterans Affairs (VA) Support for Caregivers

For loved ones of veterans and active military personnel living with a mental health condition, VA offers a wealth of resources to families to help them better understand and support their loved ones, including training and other tools. This comprehensive website offers resources by diagnosis (e.g., PTSD) and by need (e.g., [connecting](#) with other families, or learning about medications).

National Federation of Families for Children’s Mental Health

The [National Federation of Families for Children’s Mental Health](#) is a national family-run organization linking more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and their families. It was conceived in Arlington, Virginia, in February 1989 by a group of 18 people determined to make a difference in the way the system works.

PROGRAM SPOTLIGHT

Wisconsin Family Ties

Midwest nonprofit [Wisconsin Family Ties \(WFT\)](#) knows the power of family engagement. Parents of children and youth with social, emotional, and mental health needs have run this statewide organization for more than 30 years. Founded by a small group of parents on a mission to change lives by improving children's mental health, WFT offers an array of services to families across Wisconsin, such as education and training, public policy and advocacy, and support in navigating the various systems that families encounter, including the mental health system. In addition, their "warm heart fund" helps families with exceptional expenses or even basic needs that cannot be financed through another source.

WFT educates others about how best to engage and work with families to help improve the lives of the children they serve. Often, this includes helping schools and mental health systems increase their focus on the strength and resilience of children with challenging behavior and the value of their family relationships. Although WFT mainly works with children, adolescents, and transition-age youth (up to age 26), they remain available to families across the lifespan, referring those with older children to other like-minded organizations.

Central to WFT is a model of family engagement that emphasizes supporting the strength and abilities of parents. Early in the organization's life, they heard from parents that traditional models of family engagement that assumed parents needed "training" on how to parent their children were offensive and demoralizing. So WFT tried something different. They created the WI PLAN of family engagement, which focuses on empowering and supporting parents, flexibly working alongside them in areas of the parents' choosing. This model closely aligns with the [Search Institute's 6 Shifts Needed for Better Family Engagement](#).

The WI PLAN Family Engagement Model

- Welcoming & Inviting
- Listening
- Perspective shift
- Accepting
- Never giving up

Parent Peer Specialists

A dedicated team of parent peer specialists (PPSs) carry out WFT's mission across the state of Wisconsin. These paid staff members are parents of children who have used behavioral health services and know firsthand the

struggles they may encounter. PPSs approach parents with compassion and respect, and they emphasize open communication and empowerment of the families they serve.

PPSs customize their approach to each family's needs, offering help that may include liaising with parents and school or helping a family manage a crisis. PPSs undergo an initial 168 hours of training and are required to complete continuing education hours every year. A connection coordinator matches up families with a PPS in their geographic area, and then the PPS and family work together to identify goals and how WFT can help the family achieve these goals. PPS services are delivered through a six-step process that includes regular status checks with parents and a willingness to adjust plans and priorities as needed. Ultimately, their goal is to help parents gain the skills and confidence to manage on their own.

Impact of Parent Peer Support

In 2016 WFT and the Medical College of Wisconsin conducted an online survey for users of parent and adult peer support. Key questions included the following:

1. Among the services accessed, what is the relative importance of peer support?
2. Does peer support have a measurable impact on the level of engagement in other treatment or services?

The findings:

- Of the respondents, 89.5% said that peer support was "essential" or "moderately important" to them.
- Up to 87% of respondents rated the peer support they received as "highly effective" or "effective."
- Some 83% rated the quality of peer support they received as "very high" or "high."
- Of 11 services options, peer support was most frequently ranked #1 in importance (41%). Overall, 73% ranked peer support in their top three services.
- Peer specialists connected 72% of respondents with other services.
- The engagement rate in referred mental health services was 96%.

Special thanks to Hugh Davis, executive director of WFT, for contributing to this article.

THOUGHT LEADER

Sergio Aguilar-Gaxiola, M.D., Ph.D.

Dr. Aguilar-Gaxiola is the founding director of the Center for Reducing Health Disparities and a professor of clinical internal medicine at the University of California, Davis, School of Medicine. He serves as an advisor to the federal Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC). Dr. Aguilar-Gaxiola's work focuses on solutions to unmet mental health needs and associated risk and protective factors to achieve equity in underserved populations.

In the U.S., racial and ethnic minority individuals are less likely to have access to, receive, or maintain needed mental health care, according to an abundance of [research](#) across different groups. Nationwide data shows that 50 percent to 90 percent of those who could benefit from mental health services do not receive them.

One key to closing the treatment gap and helping people with serious mental illness maintain recovery is family involvement, says Dr. Sergio Aguilar-Gaxiola. Dr. Aguilar-Gaxiola has committed his career to this issue, first as a practitioner working with people with addiction and mental health and other comorbidities and now as a researcher on health disparities among diverse populations. He is a national leader in culturally and linguistically appropriate service interventions and family engagement. Family engagement, he says, is an iterative process that comprises deliberately asking about and involving the families or other loved ones of people with serious mental illness at every stage and in all aspects of treatment.

It is nearly impossible to keep someone engaged in treatment without some involvement of the family.

—Sergio Aguilar-Gaxiola, M.D., Ph.D.

Family plays a critically important role in many cultures, and even in the United States, often the family is a primary caregiver and support for adults diagnosed with serious mental illness. Incorporating the family as routine clinical practice has been shown to improve access to treatment, participation in care, integration of care, and ultimately the [outcomes of people diagnosed with a serious mental illness](#). A family-focused approach can be as simple as greeting family members in the waiting room with coffee and cookies or can include (with the permission of the person receiving the services) meeting both together and one-on-one with a family member,

such as a person's spouse or parents. It is best to take it family-by-family and explore what type and degree of involvement best fit the needs and preferences of each person using services and their family.

Understanding illness and recovery in the context of one's culture is important for truly engaging families, says Dr. Aguilar-Gaxiola. Cultural patterns affect thinking, feeling, and behavior in obvious and subtle ways, he notes. The way a family eats, works, and relates is often tied to their culture, along with their understanding and acceptance of physical and mental illness and how that illness plays into intergenerational dynamics and traditional roles of children and parents, gender dynamics, and extended family.

According to Dr. Aguilar-Gaxiola, it is not uncommon for mental illnesses to affect multiple family members. For example, a teen with depression may report a parent or sibling with similar experiences. Behavioral health practitioners should regularly ask if other family members have or have had similar problems. This is critical information for understanding a person and is important to helping them achieve recovery.

The benefits of meaningful family engagement are many. Research comparing standard outpatient treatment without family involvement to that with a family psychoeducation component found that family psychoeducation resulted in up to a [75 percent reduction](#) in rehospitalization. Family members had improved health, too: there was an up to 50 percent reduction in doctors' visits for family caregivers in one year. Engaging and incorporating the family in a culturally appropriate manner across clinical settings can improve access to treatment, integration of care, and ultimately, the clinical outcomes of patients with serious mental disorders.

WHAT YOU CAN DO

EDUCATE

[Research on family psychoeducation](#) consistently shows that it improves outcomes and reduces hospitalizations for individuals diagnosed with serious mental illness. SAMHSA has [resources](#) to help you implement family psychoeducation in your programming.

ENGAGE FAMILY COACHES AND PEERS

Although there is a nationwide shortage of behavioral health providers, there will always be people who have personal experience loving and caring about a person living with a serious mental illness. Seek them out through your internal networks or groups like NAMI and see if they want to mentor or help the families you work with in other ways.

UNDERSTAND A FAMILY'S CULTURE

Although every family is unique, it is helpful to learn more about traditional family structure and beliefs of the individuals you work with through resources such as the [UC Davis Center for Health Disparities](#) or the [National Network to Eliminate Disparities in Behavioral Health](#). The [APA DSM-5 Cultural Formulation Interview](#) is a tool to help practitioners understand the role of one's culture in their condition. You can watch a Recovery to Practice webinar on this topic on the [SAMHSA RTP website](#).

CREATE A FAMILY INVENTORY

"Family" does not always mean blood relatives. Ask individuals using services: "Who do you rely on in a crisis? Who is an important part of your daily life? Who do you want to know about and be involved in your treatment?" The definition of family should be determined by the individual using services.

RECOGNIZE THE POWER OF FAMILY RELATIONSHIPS

When working with families, keep in mind that some parents will do absolutely anything for the safety and well-being of their child. Sometimes well-meaning family members can unintentionally impede the process of recovery. Nonjudgmental empathy and understanding go a long way in creating a trusting relationship.

CONFERENCES & EVENTS

Engagement Webinar Series

RTP is hosting a series of four webinars on Engagement in Spring 2018.

- **April 4, 2018:** Therapeutic alliance and its impact on engagement
- **May 7, 2018:** Pre-crisis/crisis and engagement using WRAP
- **May 23, 2018:** Using social media and other technology approaches for outreach and engagement

For more information, visit the RTP website at <https://www.samhsa.gov/recovery-to-practice>.

American Occupational Therapy Association (AOTA) Annual Conference and Expo

April 19-22, 2018, Salt Lake City, Utah

Visit the [site](#) to learn more or register to attend.

APR
19-22

FREE CME: NEW ON-DEMAND COURSE!

Clinical Decision Support: Clozapine as a Tool in Mental Health Recovery is a continuing education course that offers information and resources for physicians, clinicians, and other practitioners serving patients with psychotic symptoms who may be considering taking clozapine. [Learn more!](#)

FREE

Also check out our other CME courses: Clinical Decision Support for Providers Serving Individuals with Co-occurring Disorders [Course 1](#) and [Course 2](#).

MODELS FOR FAMILY ENGAGEMENT AND INVOLVEMENT

- [Family psychoeducation \(FPE\)](#): An approach based on partnering with individuals and their families to develop a strong working relationship based on knowledge and mutual goals.
- [Consumer-centered family consultation \(CCFC\)](#): An information and skill-oriented approach to engaging families in which practitioners and individuals using services work together to involve the family in care.
- [Family-centered care \(FCC\)](#): An approach to general health care decision-making, which is most often used with children, that involves respect, information sharing, collaboration, negotiation, and honoring the family, including any behavioral health concerns.