

Issue Brief: Supporting Families and Caregivers of Adults with Serious Mental Illness

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INTRODUCTION

The World Health Organization (WHO) estimates that one in four families worldwide includes at least one member who has been diagnosed with a mental illness and that these illnesses will constitute the largest global burden of disease by the year 2020 (Murthy et al., 2001; Shamsaei, Cheraghi, & Esmaeili, 2015; Whiteford, Ferrari, Degenhardt, Feigin, & Vos, 2015). While the majority of individuals with mental illness lead healthy, productive lives with minimal support, a subset requires substantial assistance with major life activities.¹ More than eight million Americans provide support to loved ones with serious mental illness (SMI; National Alliance for Caregiving [NAC], 2016; Treatment Advocacy Center, n.d.). This issue brief explores the roles and needs of families and caregivers of adults with SMI, and it describes promising practices for supporting them. Family members and caregivers may be parents, siblings, partners, adult children, or others providing unpaid care and support for adults with SMI. For ease of reading, we will use the term “family” as shorthand for all of these.

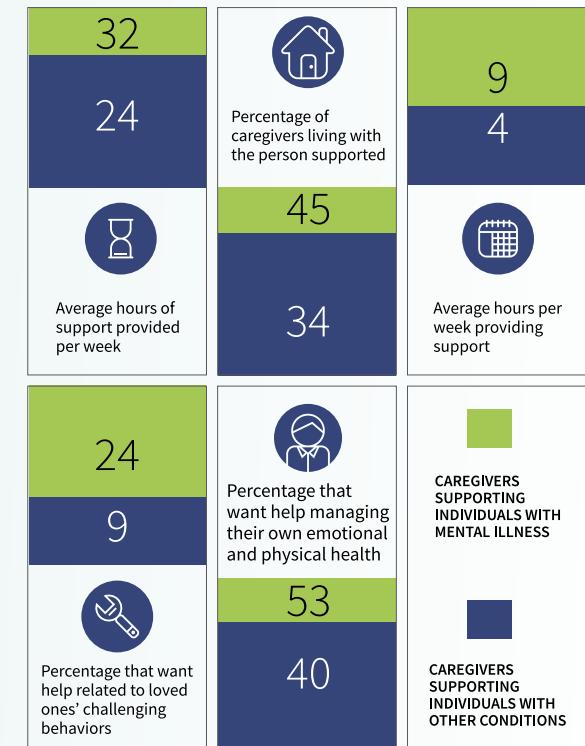
¹ Major life activities include basic daily living skills (e.g., eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts (National Alliance for Caregiving, 2016; Samuel, Thomas, & Jacob, 2018).

WHO ARE THE FAMILIES, AND WHAT ARE THEIR ROLES?

Family roles fluctuate, given the dynamic nature of recovery. Families may take care of the day-to-day needs of their loved ones, provide emotional and social support, monitor symptoms, and help them access services. Families may arrange or coordinate treatment, and they may help with treatment costs or transportation to and from appointments. In addition, many families provide material and financial support (Gerson & Rose, 2012; Shor & Birnbaum, 2012).

The National Alliance for Caregiving (NAC), in collaboration with the National Alliance on Mental Illness (NAMI) and Mental Health America, surveyed more than 1,600 individuals providing support to adults living with mental illness to learn about these family caregivers and the types of support they provide. Family caregivers are typically middle-aged (average 54 years old, ranging from 45 to 64 years old) and often caring for adult sons or daughters (45 percent; NAC, 2016; NAC & AARP Public Policy Institute, 2015). A significant but smaller group support their parents (14 percent), spouses (11 percent), or siblings (9 percent; NAC, 2016). Overall, American families of adults with mental illness provide more support for longer periods of time and at a closer range than those who provide support for people with other health conditions (see Table 1).

Table 1: Differences between families caring for adults with mental illness and families caring for adults with other conditions



Adapted from the National Alliance of Caregiving 2016 report, *On Pins and Needles: Caregivers of Adults with Mental Illness*

BRSS TACS
Bringing Recovery Supports to Scale

TECHNICAL ASSISTANCE CENTER STRATEGY

SAMHSA
Substance Abuse and Mental Health Services Administration

“One of the biggest benefits [of being a caregiver] is knowing that your family member is being treated with love and respect and getting the care they need.”

—Family Caregiver Quote



HOW DOES CARING FOR ADULTS WITH SMI IMPACT FAMILIES?

While research on the benefits of caregiving for adults with mental illness is limited, qualitative studies indicate that caregivers have more compassion for others with chronic mental illness, additional knowledge of mental health issues, and feelings of accomplishment (Anderson & White, 2018; Ross, 2012; Schulz & Sherwood, 2008). They also report an increased sense of personal satisfaction and meaning, improved skill levels, and strengthened relationships (Cotton, 2015; Hayes, Hawthorne, Farhall, O’Hanlon, & Harvey, 2015; Schulz & Sherwood, 2008).

At the same time, life may be unpredictable or even, at times, chaotic for family caregivers. A loved one’s long-term journey to claiming or reclaiming a meaningful and satisfying life may include periods of progress toward that goal, followed by unexpected relapses, however brief, or long periods when little seems to be moving forward. The unpredictability of the journey can leave families feeling powerless and unable to do much but worry about the person they love. Families may worry about their loved one becoming homeless, dying by suicide, or becoming involved or re-involved with the police and the courts (Copeland & Heilemann, 2011; Spaniol & Nelson, 2015). This ongoing stress and anxiety can take a physical and emotional toll on the caregiver. Three out of four family caregivers report that caring for their loved one is emotionally stressful, and more than half report that caregiving has worsened their own health (NAC, 2016).



FAMILY NEEDS AND PROMISING PRACTICES

Social Support

Many family caregivers report a sense of isolation and lack of social support that can worsen over time (Akbari, Alavi, Irajpour, & Maghsoudi, 2018; Diehl, Niles-Yokum, & Caldwell, 2018; Hayes et al., 2015). Some report that friends and relatives avoid spending time with them due to negative misperceptions about their loved ones (Chadda, 2014). Networking and cultivating social support require time that stressed families often do not have when juggling jobs, caregiving, and other family responsibilities. Joining in commonly organized activities that usually lead to social networks, such as religious groups or leisure time activities, are not possible within the time available for many families. As a result, the most beneficial—albeit somewhat limited—method of creating supportive networks is sometimes through the tasks associated with

“People stop coming to the house. Even close relatives are reluctant to come.”

—Family Caregiver Quote

caregiving. Some online support is available for caregivers through the Family Caregiver Alliance and other organizations, as well as in-person support from organizations such as NAMI. Peer-delivered services may also have important benefits for family members and for individuals living with mental illness (NAC, 2016; Ross, 2012). Getting support from other family members is not a substitute for psychoeducation from professionals, but through peer education, families can relate to each other's lived experiences in ways that professionals cannot (Gonzales, 2016; Schiffman et al., 2015). The most well-known example of such a program is Family to Family, a 12-week psychoeducational and skill-building group developed by NAMI. Dixon et al. (2011) found significant improvements in knowledge about mental illness and problem-focused coping among family members who took part in Family to Family.

Some family caregivers express that the level of anonymity in online groups encourages them to participate more and share their experiences more comfortably than they would in in-person support groups (Bauer, Bauer, Spiessl, & Kagerbauer, 2013; Gonzales, 2016). Study findings show that social support can be regarded not only as a protective factor in reducing the caregiving burden for family caregivers, but also in promoting caregivers' quality of life (Raymond, 2016; Zeng, Zhou, & Lin, 2016).

Finances

Family caregivers report that financial constraints are a major challenge. Some family members depend on charity and loans from their relatives for survival, as they have no source of income. Others are obliged to quit their jobs in order to fulfill their caregiving responsibilities (Shamsaei et al., 2015; Song, Mailick, & Greenberg, 2014). Families' financial stress and worries about meeting the daily living needs of their loved ones may lessen if the adult with SMI obtains Social Security Disability Insurance (SSDI). However, some adults with SMI are not willing to apply for these benefits, particularly if they do not consider themselves to be living with a disability (Bragen, 2011; Corrigan, Watson, & Barr, 2006). A limited number of programs exist to help caregivers with financial challenges. Some programs help with providing direct financial support. For military families, the VA Program of Comprehensive Assistance for Family Caregivers provides some financial support for family caregivers living with the person for whom they provide care (Ramchand et al., 2014; U.S. Department of Veterans Affairs, 2017). Long-term care insurance policies through some insurance companies provide limited salary coverage for a caregiver to support “disability in place.” The difficulty is that such insurance is currently mostly designed for medical issues and is costly.

In terms of supporting family caregivers' ability to work, the Family Medical Leave Act (FMLA) provides job security for those who need to take time off to care for loved ones—but it is problematic for families of individuals with chronic conditions, since it is time limited to 12 weeks and does not apply to individuals caring for adult siblings.

Information and System Navigation

Many family caregivers struggle with accessing or knowing if they have accessed credible information and high-quality treatment and recovery supports for their loved ones and themselves. Family caregivers frequently express confusion when trying to navigate the complex and fragmented mental healthcare system. They also describe frustration with the lack of information about their loved one's illness, and a need for additional help with managing illness, medications, and associated crises to reduce the incidence of relapse and rehospitalization (Gerson & Rose, 2012; Raymond, 2016).

County and state mental illness and substance use disorder service systems, as well as health insurers, may play a key role in providing navigation assistance to individuals with mental illness and their families. Some systems and providers are also taking steps to make services more accessible and systems easier to navigate, including developing coordinated intake processes and "no wrong door" policies.

Another strategy to assist family caregivers as they navigate systems is the use of family peers (Diehl et al., 2018; Shor & Birnbaum, 2012). Family peers are seasoned caregivers who can support and provide information to other families. While this approach is widely used for family caregivers of children, its use is limited for families caring for adults with mental illness.



Mental and Physical Health

Families of adults living with mental illness identify the need for help with managing their own emotional and physical stress more often than those supporting individuals with other health conditions (53 percent versus 40 percent; NAC & AARP Public Policy Institute, 2015). Depression, stress, and low ratings of well-being are associated with variables such as the duration and amount of care provided, the caregiver's age (with older caregivers being more affected), the relationship between the caregiver and the individual they support (with a spousal relationship having a greater effect), and the caregiver's gender (with females being more affected; Sharma, Chakrabarti, & Grover, 2016; Swinkels, van Tilburg, Verbakel, & van Groenou, 2019). For many family caregivers, guilt about any time they spend away from their loved ones appears to reduce their own health-promoting behaviors, such as exercising, eating well, and even attending medical or dental appointments.

Recommendations to address this challenge include the provision of respite services and integrated healthcare models that are inclusive of family caregivers. Respite gives family caregivers time to take care of their own needs and health care; exercise; run errands; and spend time with their children, spouses, and friends (Jeon, Brodaty, & Chesterson, 2005; National Academies of Sciences, Engineering, and Medicine, 2016; Raymond & Kagan, 2015).

Healthcare provider organizations are launching new initiatives in collaboration with other industries to improve access to healthcare services while, for example, shopping for daily goods. Innovations like these may eliminate the barrier of time if they offer services in places families are already visiting (Payne, 2018; Pearson, 2018).



Involvement with Loved Ones' Treatment and Services

Many family caregivers have difficulty communicating with the professionals working with their loved ones (Diehl et al., 2018; Spaniol, 2010). Medical professionals may also face a similar dilemma in terms of knowing with whom to communicate or in not realizing that they are legally able (and in some situations, required) to speak with the family (Diehl et al., 2018; Szabo, 2016). As noted by the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC), there is a need to educate professionals about the value and need for communication with family caregivers, as well as the types of disclosures of protected health information that are permitted in the context of a psychiatric crisis (ISMICC, 2017).

In addition to the complexity of privacy issues, practitioners often have strictly limited amounts of time to spend per individual, due to funding or their agency's billing structure. These limits make them less likely to include families in any substantial way, either because they cannot bill for these services, or because they determine that they do not have enough time to include the families (National Academies of Sciences, Engineering, and Medicine, 2016).

Research indicates that when family caregivers' needs are attended to, the outcomes of individuals with SMI improve, yet the needs of families often go unnoticed or unaddressed by professionals working with adults with SMI. Treatment is generally determined by the needs and condition of the person receiving care, so family needs are not often identified (American Psychological Association, n.d.);

ISMICC, 2017; Shamsaei et al., 2015). More and more families are looking to professionals for help. Interventions for families should be considered as part of integrated services for people with SMI (Pharoah, Mari, Rathbone, & Wong, 2010; Yesufu-Udechuku et al., 2015). Providing interventions and training to help families prepare for common challenges, such as difficult behaviors and medication management, can protect the safety of adults with SMI as well as their families. While the overall research is currently insufficient, the literature on supports for families of adults living with SMI implies that multi-component interventions that include web-based and live support, blending psychoeducation, mutual social interaction, individual professional assistance, and opportunities for loved ones' engagement in roles that support others, may help individuals, families, and communities in working to address problems and enhance their well-being (ISMICC, 2017; National Academies of Sciences, Engineering, and Medicine, 2016; Shah, Wadoo, & Latoo, 2010).

Family psychoeducation, provided by a mental health professional, helps family members by providing them with information about mental illness and recovery, as well as teaching them coping strategies, stress management techniques, and self-care skills (Chadda, 2014; Soliman, Mahdy, & Fouad, 2018). And, because the symptoms, challenges, and conditions of their loved ones with SMI may evolve over time, families need information on changing diagnoses, medications, and crisis intervention (Shamsaei et al., 2015; Yesufu-Udechuku et al., 2015).

Planning for the Future

Many family caregivers worry about how their loved ones will be supported when they are no longer able to help them due to their own health problems, aging, or eventual death. The majority of family caregivers do not have plans in place for their loved ones' care should circumstances occur that render them unable to provide care. Only 36 percent of family caregivers indicate that their family member has plans for their own future care (NAC, 2016). Help in future planning for caregivers, including those providing support for people living with mental illness, can be accessed online through the National PLAN Alliance, which has collaborated with NAMI and other organizations in 22 states (Hewitt et al., 2010; National PLAN Alliance, n.d.).



RECOMMENDATIONS



For Policy Makers

- Review and revise the FMLA to lengthen the amount of time allotted and to include sibling care as an allowable benefit.
- Research the provision of respite care as provided for families of individuals with intellectual disabilities, and utilize this as a model for families of adults with SMI.
- Develop peer support and system navigation services for family caregivers of adults with mental illness that mirror services for families of children with mental health needs.



For Practitioners/Providers

- Create curricula in graduate and medical schools, continuing education, and in-service training focused on family supports, including the provision of holistic treatment planning.
- Include family psychoeducation and support in service offerings.
- When developing plans with adults with SMI, discuss options for involving or communicating with their families, understanding that this need not be an “all or nothing” decision. Some adults may want their families to be involved in treatment decisions; others may want them to be involved only with financial matters or in crisis situations (Hawke, Pearson, Ratliff, & Walker, 2018).
- Collaborate with peer- and family-run organizations to provide supports and education, and to create family-friendly educational resources.



For Peer- and Family-Run Organizations

- Offer peer-led support groups and/or peer mentoring for families of adults with SMI. Talking with and building relationships with peers provides relief from isolation, as well as the opportunity to learn from other caregivers who may have suggestions.
- Collaborate with providers and practitioners to provide referrals to treatment and services and to create family-friendly educational resources.
- Develop training, information, and resources for families to support them in addressing identified needs, including credible information about treatment and recovery support options, caregiving skill development, financial resources and planning, respite, and future planning.



CONCLUSION

Families provide critical supports for adults with SMI (Chadda, 2014; NAC & AARP Public Policy Institute, 2015). Recognizing and meeting the needs of families may improve family functioning, reduce caregiver strain, and improve outcomes for adults with SMI (Acri, Zhang, Adler, & Gopalan, 2017; Family Caregiver Alliance, National Center on Caregiving, 2006).

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Please share your thoughts, feedback, and questions about this publication by emailing BRSSTACS@c4innovates.com. Your feedback will help SAMHSA develop future products.

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