

# SUPPORTING FAMILIES AND CAREGIVERS OF ADULTS WITH BEHAVIORAL HEALTH DISORDERS

## KEY POINTS

- Caregivers of people with behavioral health disorders provide support across all domains of life, including housing, finances, legal assistance, care management, and clinical support, often throughout the care recipient's life.
- There is a high level of desperation expressed by behavioral health caregivers, as many fear their loved ones may die, experience homelessness, or be incarcerated.
- This fear is in part attributable to the limited availability of quality behavioral health care and the increased, but unmet, need for care coordination and information sharing.
- Increased support for these caregivers could improve the behavioral health of their loved ones, ease the burden on behavioral health treatment providers, and ameliorate the physical and behavioral health challenges of caregivers themselves.

In 2019, an estimated 13 million people in the United States provided unpaid care for an adult family member or friend with mental health problems (AARP & NAC, 2020).<sup>1</sup> Estimates are not available for the number of people supporting the more than 44 million adults in the United States with substance use disorders, but it is likely a substantial group (SAMHSA, 2023a). There is limited research on the population who provides care and support for adults with behavioral health disorders (defined as mental health, substance use, or co-occurring mental health and substance use disorders; however, the research does show they face many challenges, resulting in high caregiver stress and strain (NAC, 2016). Additionally, little is known about the unique risks and experiences of people supporting adults with behavioral health disorders (behavioral health caregivers) as compared to other caregiver groups. Moreover, current programs and interventions that support behavioral health caregivers are limited in scope and availability.

To better understand the challenges behavioral health caregivers face and potential policies to support them, the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services commissioned a technical expert panel (TEP) and a targeted environmental scan. This brief presents key themes that emerged from this work regarding the following:

- Challenges behavioral health caregivers face.
- Existing programs and interventions to support behavioral health caregivers.
- Opportunities to address gaps in supports for behavioral health caregivers.

<sup>1</sup> This brief is based on an environmental scan of articles, reports, guidance, and other relevant academic and grey literature published since 2017, supplemented with older resources to fill specific gaps in information. Few recent reports describe the unique challenges and needs of behavioral health caregivers. As the primary references of their kind, two reports (AARP & NAC, 2020; NAC, 2016) feature prominently in this brief.

Although behavioral health caregivers share some experiences with caregivers of adults who have other conditions, this project sought to better understand the challenges that are particular to the behavioral health caregiver population and the opportunities to better serve them.

## TYPES AND LEVEL OF CARE PROVIDED BY BEHAVIORAL HEALTH CAREGIVERS

Caregivers perform a wide variety of tasks to meet the individual needs of the person receiving support (ACL, 2023), often assisting with activities of daily living (e.g., bathing, eating, dressing) and instrumental activities of daily living (e.g., bill paying or making appointments). Behavioral health caregivers in particular often play a primary part in the care recipient’s recovery, helping them seek and engage with behavioral health services. Like other caregivers, they often address additional needs including emotional and social support, advocacy, and care coordination (Schulz, 2016).

The technical expert panelists echoed and expanded upon these findings. They noted these caregivers frequently provide practical supports, such as direct housing and financial assistance. Additionally, panelists indicated that behavioral health caregivers often function as de facto care managers or navigators, spending considerable time and resources identifying and facilitating access to services, coordinating care across providers, monitoring care quality, informing providers about the care recipient’s treatment history and symptoms, and advocating for the care recipient to have a voice in their own care processes. They may encourage the care recipient to connect with and engage in treatment, services, work, and school. According to panelists, behavioral health caregivers may also address the clinical needs of their care recipients directly, such as by managing medications. Panelists also reported that caregivers may engage with their loved one in ways that model clinician-provided care, such as using cognitive behavioral therapy techniques, de-escalation techniques, helping development of coping strategies, and teaching daily living skills.

### Common Supports Provided by Behavioral Health Caregivers

- Housing, relocation assistance, and supports to prevent eviction.
- Meals.
- Financial support and money management.
- Transportation.
- Legal assistance and assistance navigating involvement with the criminal justice system.
- Medication management.
- Care management, system navigation.
- Monitoring quality of care.
- Socialization, recovery support, and efforts to improve quality of life.
- Self-advocacy.
- Motivation.
- Clinical support.

Behavioral health caregivers provide care for longer periods of time and for more hours per week than caregivers of those with other conditions. For example, almost half (48%) of behavioral health caregivers reported providing care for 5 or more years, a much greater percentage compared to caregivers of other populations, such as individuals over 65 or with cognitive disorders (Timko et al., 2022). In one study of caregivers of individuals with mental health disorders and no co-occurring SUD (mental health caregivers), one in three caregivers reported providing care for more than 10 years (AARP & NAC, 2020). Panelists also acknowledged the long duration of caregiving responsibilities, highlighting that behavioral health caregiving often spans the care recipient’s lifetime and therefore might require transitions from one caregiver to another.

For example, caregiving might initially be provided by the care recipient’s parent or guardian, pass on to their siblings or spouses, and ultimately pass to the care recipient’s own children.

The TEP attributed differences between the level and duration of care provided by behavioral health caregivers and other caregiver groups to several factors. First, behavioral health caregivers more often live with the recipient of their care (45%) than other caregiver groups do (32%), which could result in more opportunities for providing support (NAC, 2016). One panelist noted, for example, that behavioral health caregivers provide more hours of care because they are with their care recipient daily. Another reason they provide so much care is in part because behavioral health disorders are less predictable than other conditions. In addition, one panelist noted, “You may be the only person there for the person [receiving care].” Panelists also cited the early onset and chronic nature of many behavioral health disorders as contributing to more years of care provision.

## CHALLENGES FACING BEHAVIORAL HEALTH CAREGIVERS

A broad body of literature describes the challenges of informal, unpaid, and/or family caregivers generally, but less information is available about those particular to behavioral health caregivers. According to both our research and the panelists’ experiences and expertise, behavioral health caregiving differs from other types caregiving. As described in greater detail below, the difficulties most people face in accessing treatment and support services, gaps in information and education needed to support caregivers, and length and intensity of caregiving may distinguish behavioral health caregiving. Additionally, these caregivers may experience trauma in the face of such unique risks as self-harm, suicide attempts, and criminal justice involvement on the part of the person for whom they provide care. In those challenges that occur across caregiver populations, we often identified a difference in degree. For example, existing research and the technical expert panelists advise that caregiving for someone with a behavioral health disorder often has more severely deleterious effects on the caregiver’s well-being compared with other caregiving groups. Our findings indicate this correlates with behavioral health caregivers greater experience of stigma, isolation, and lack of empathy from friends and other family members.

### ***Unique risks of behavioral health disorders and difficulties accessing behavioral health treatment and support services***

Concern about the general well-being of the care recipient contributes greatly to behavioral health caregiver burden and stress. The availability of appropriate services and supports for that person, or lack thereof, may also weigh on caregivers. Like other people with chronic conditions, individuals with behavioral health disorders often require services from multiple health and social care systems. However, caregivers of those with behavioral health conditions report challenges accessing and coordinating services for the recipient of their care more frequently than other caregiver groups to (AARP & NAC, 2020), illustrating the complexity of service and social support needs among this population. Panelists pointed out that people with behavioral health disorders often have significant physical health care concerns related to the behavioral health disorder that also need to be treated and necessitate further care coordination. They noted conditions such as diabetes, cardiac issues, liver problems, and metabolic syndrome are common among these individuals.

*“Even if [the care recipient is] 40 years old and supposed to be an independent adult, you can’t give up on your child.”*  
*“If you kick them out, they might wind up dead.”*  
*“I’m watching them. They’re going to die, and there’s no way for me to intervene.”*

— TEP member

Finding behavioral health care providers can be extremely challenging, particularly in rural communities. One panelist noted that their community has not had a psychiatrist for 7 years. Other panelists noted particular difficulty in finding services for individuals who do not qualify for Medicaid but cannot afford to pay out of

pocket. They also stated that many people with behavioral health disorders have difficulty accessing care from skilled nursing facilities or home health agencies due to discrimination. People with co-occurring mental health and substance use disorders are sometimes turned away from inpatient mental health facilities when policies exclude admission of those with substance use disorders or even co-morbid medical conditions (Hepburn, 2023). People with significant needs are turned away even when their life is at risk: one panelist described someone with an active suicide plan being released from an emergency department because they were using substances. These barriers to care risk not only the safety and well-being of the care recipients, but the caregivers as well.

In many communities with behavioral health provider shortages, the main treatment setting may be a jail or prison. Indeed, jails are the largest mental health care providers in the country (National Center for State Courts, 2020). Engagement with the justice system is more common among people with behavioral health conditions, particularly substance use disorder. Their caregivers thus face the largely unique challenge of navigating criminal and legal services as well as the health and social services described above. (Bixby et al., 2022). Panelists also noted that those who have been incarcerated or otherwise involved with the criminal justice system may suffer even greater isolation than other care recipients, further impairing their emotional well-being.

Housing poses another unique concern for people with behavioral health conditions and their caregivers (Bixby et al., 2022). Panelists reflected on housing and related issues as particularly challenging for caregivers. Difficulties include not only the costs of directly housing or arranging housing for their loved one, but also the uncertainty around their ability to remain housed. For example, some panelists discussed how stigma against people with behavioral health disorders increases the chances of them being evicted for minor infractions that might be tolerated for other residents. Eviction could be grounds for losing housing subsidies, threatening the individual's ability to maintain housing or acquire it in the future (Clark, 2007; Moore & Gammell, 2023). Additionally, if an individual has been involved in the criminal justice system, obtaining and retaining housing is even more difficult. The associated threat or occurrence of homelessness is another source of caregiver stress, according to panelists. Homelessness may result in the caregiver and care recipient losing contact. This can increase risk of harm, justice involvement, and worsening of symptoms for the person with a behavioral health condition and increased stress, concern, and desperation for their caregiver.

Caregivers also express fear that their loved one will die by suicide, harm themselves, or be victimized by others far more often than other caregiver groups (AARP & NAC, 2020; NAC, 2016). With substance use disorders, including with co-occurring mental health conditions, caregivers face the additional fear of death from overdose (Labrum, 2018). Panelists described caregivers worrying even while the care recipient is in recovery because they are waiting for the next crisis.

Finally, behavioral health caregivers often express concern about what will happen to their loved one if the caregiver is no longer able or willing to support them. Panelists stated they hear this most often from older caregivers or those with their own health care needs.

### ***Gaps in information and education***

Behavioral health caregivers often express feeling ill-equipped in their roles. Although they are more likely to seek training and education than caregivers of other populations, 39% of respondents in a survey of mental health caregivers reported that they received no education or training on how to manage their care recipient's mental health condition (AARP & NAC, 2020; NAC, 2016). Panelists added that caregivers may be unaware of increased risks to their own safety and their loved one's due to, for example, resumption of substance use. This can be caused or exacerbated by providers not understanding what information they may share with the caregiver.

Gaps in provider training, education, and understanding of behavioral health disorders contribute to caregiver challenges. Providers are sometimes hesitant to discuss a person's treatment with their caregivers because of real or perceived limitations on information sharing, mentioning the Health Insurance Portability and Accountability Act (HIPAA) of 1996 as a barrier. Although HIPAA does not prevent providers from receiving information from caregivers about the recipients of their care and permits exchange of information with the recipient's consent, uncertainty about the boundaries of information sharing between providers and caregivers creates barriers that behavioral health caregivers must overcome (Office of Civil Rights, 2024). Such uncertainty may increase when care recipients have a substance use disorder, due to additional confidentiality requirements under 42 CFR Part 2 (the Confidentiality of Substance Use Disorder Patient Records regulations). Changes made to better align Part 2 with HPA rules via a 2024 Final Rule could help reduce this added confusion. Panelists also noted the following:

- A pronounced lack of recognition among providers of the significant role behavioral health caregivers play in the lives of the recipients of their care. More pointedly, one panelist said providers do not give caregivers credit for keeping the care recipient alive. Lack of communication from providers leaves caregivers not knowing how well or poorly the care recipient is doing and what they need to follow through with. This is often a barrier for the progression of the care recipient's wellness.
- Challenges in getting providers to engage with caregivers *before* their loved one is in treatment. Doing so could help caregivers understand how to encourage and motivate their loved one to enter treatment. But providers may not understand the importance of this and are often unwilling to meet with caregivers of people to whom they are not providing services because of reimbursement or other concerns.
- Non-English and English Second Language speakers are especially likely to be excluded and subject to misunderstandings arising from cultural and language barriers. Caregivers with less formal education may also not understand the terminology used by providers.
- The need for provider education and training regarding caregiver involvement is not limited to behavioral health providers. Panelists reported that primary and other physical health care providers often do not understand mental illness and the need to involve caregivers to ensure communications are received and acted on.

### ***Effects of caregiving on the caregivers' well-being***

Behavioral health caregivers reported poor general physical and mental health and face frequent limitations on their non-caregiving activities (Timko et al., 2022). In addition, they were more likely to receive a diagnosis of depression and to report binge drinking than other caregiver groups (Timko et al., 2022). A survey of mental health caregivers found that 75% of mental health caregivers reported that providing care for their loved one has caused them emotional stress, and 25% reported feeling increased physical strain (NAC, 2016). Panelists explained that behavioral health caregiving can expose caregivers to traumatizing experiences, such as witnessing suicide attempts or other tragedies, that require support for the caregiver's own mental health and well-being. Stress can also have cumulative effects on physical health. Only 33% of mental health caregivers reported their own health as excellent or very good, which is lower than the same figure for United States caregivers for all conditions (NAC, 2016). More than half reported feeling their role has made their own health worse, significantly more than the 22% of other caregivers who expressed the same (NAC, 2016). The stress of caring for another person is compounded when simultaneously managing one's own condition. Caregivers of those with co-occurring mental health and substance use disorders reported having more difficulty caring for their own health and felt more alone as a caregiver than those caring for people with mental health disorders alone (Labrum, 2018).

Panelists highlighted several unique aspects of behavioral health caregiving that might contribute to the differences in outcomes for behavioral health caregivers relative to other caregiver groups. One of these aspects is the stigma associated with behavioral health conditions that caregivers commonly experience, referred to as “affiliate stigma” or “stigma by association” (Zhang et al., 2018). Stigma, real or perceived, influences behavioral health caregivers’ ability to seek out needed support, socially isolating them. In one survey, for example, nearly half the mental health caregivers reported difficulty discussing their care recipient’s condition or needs because of stigma, and adult children of parents with mental health conditions reported that stigmatization discouraged them from seeking support (NAC, 2016; Widemalm & Hjärthag, 2015). Caregivers encounter stigma not only from friends and acquaintances but also from health care providers (Coombs et al., 2021), depriving them of the empathy commonly conveyed to those caring for people with other conditions.

Compounding the isolating effects of stigma is the difficulty maintaining friendships because of the amount of time that caregiving requires. Panelists also described strains on family relationships that can further isolate

*“The isolation is profound. A certain amount of it becomes almost self-inflicted over time... because there is so much stigma and discrimination that you reach a point where you hesitate to just tell people what’s going on with your loved one, because there are some folks where there’s still that sense of you [as the caregiver] need to just tell [your loved one] to sink or swim. When you’re consumed with those fears... I’ve already intervened in a suicide attempt, and I’m living with some PTSD from that hyper-vigilance and then to have someone’s response be well, if you just kick them out or cut them off, they’ll figure it out... but you’re thinking my loved one might wind up dead. So, I think there are times that you don’t share, you don’t ask for support. You’re self-limiting because sometimes the response can be soul crushing.”*

— TEP member

caregivers. For example, conflicts can arise among multiple caregivers or between the caregiver and the care recipient regarding treatment decisions. Because the care recipient has an outsized impact on family dynamics and attention, conflicts can also arise with siblings of the care recipient who might withdraw, move away, or no longer stay in touch. Family members might also live apart for better access to care and become estranged. Marriages can dissolve, and families can splinter. Panelists described an intense amount of emotional labor in managing these complex family dynamics.

Behavioral health caregivers assume significant financial burden associated with their role. Nearly half of mental health caregivers reported that the recipient of their care financially depends on them (NAC, 2016). In all, 25% reported high financial strain because of providing care compared with 16% of caregivers of adults without mental health issues (AARP & NAC, 2020). One panelist said that the “financial impacts are extreme.” Panelists also cited

the costs of housing care recipients as well as lost opportunity to build retirement savings. If caregiving prevents or lowers time at work, financial impacts can also include the inability to accumulate sufficient credits for paid work to qualify for Social Security retirement benefits.

Overall, panelists described a level of desperation among behavioral health caregivers that is not common to caregivers of people with other conditions, attributable in part to the challenging course of behavioral health conditions and recovery. Panelists shared that behavioral health caregivers often anxiously await the next crisis, and when tragedies or losses occur, caregivers often blame themselves, saying, “If only I had been there more.” Panelists reflected on how caregivers have difficulty building a life for themselves while in this role, wondering how to fit in a walk, good meals, making music, or handling relationship issues. These are not only tasks of daily living but also things one does to make life worthwhile. Panelists shared that caregivers may lose hope and become overwhelmed.

## EXISTING PROGRAMS AND INTERVENTIONS TO SUPPORT BEHAVIORAL HEALTH CAREGIVERS

The most widely available programs and interventions designed to support behavioral health caregivers are peer mutual support groups. Peer support can alleviate the isolation and stigma that many family caregivers have expressed in caring for a loved one with mental illness (NAC, 2016). A panelist reported that the National Alliance on Mental Illness (NAMI) recently collected data from participants in its family support groups and peer support groups and that, when asked what the group gave them, almost all participants said, “Hope.” The panelist said that providing hope can help people stay engaged in caregiving longer than they otherwise would. In addition to mutual support groups, some communities are beginning to pay family peer support specialists to provide one-to-one support to families of adults with behavioral health conditions.

*“We interviewed participants and their family members... and the thing that I took away, and I could most relate to personally was this notion of what we called the cloud of uncertainty. The whole background of everything that was going on, it's the stress and the strain and the fear and the confusion. It was so consistently observed in this qualitative work. Even if caregivers are knowledgeable, they are uncertain.”*  
 — TEP member

**Table 1: Programs and Interventions Benefiting Caregivers**

Program or Intervention	Targeted Group	Description
<b>Peer Support</b>		
Al-Anon Family Groups	People whose lives have been affected by someone else’s drinking	A 12-step mutual support program based on core principles conveyed through fellowship and reading materials.
Alateen	Young people (mostly teenagers) whose lives have been affected by someone else’s drinking	A 12-step mutual support program based on core principles conveyed through fellowship and reading materials.
NAMI Family Support Groups	Family members, significant others, and friends of people with mental health conditions	Peer-led groups that offer participants an opportunity to share their experiences and gain support from other attendees.
Nar-Anon Family Groups	Family and friends of people with addiction problems	A 12-step mutual support program based on core principles conveyed through fellowship and reading materials.
Narateen	Teenage family members and friends of people with addiction problems	A 12-step mutual support program based on core principles conveyed through fellowship and reading materials.
Suicide Bereavement Support Groups	Suicide loss survivors	Examples are available on the American Foundation for Suicide Prevention’s website, including the online support group Alliance of Hope for Suicide Loss Survivors.
Family Peer Support Specialist Services	Families of people with behavioral health disorders	Certified paid specialists with lived experience as caregivers provide instrumental, social, and informational support to reduce isolation, shame, and blame; help people navigate service systems; and provide other relevant life experiences. It is broadly supported for parents of children with behavioral health disorders and gaining traction for families of adults with behavioral health disorders.
<b>Education Programs</b>		
Families Empowered and Supporting Treatment for Eating Disorders (F.E.A.S.T.), 30 Days Program	Parents and caregivers of people with eating disorders	Designed to educate and empower families and caregivers by providing a deeper and more robust understanding of what eating disorders are, how they are treated, and how they can best support their loved ones.

**Table 1 (continued)**

<b>Program or Intervention</b>	<b>Targeted Group</b>	<b>Description</b>
Family Psychoeducation (Dixon et al., 2001)	Family members and others involved in the lives and care of adults with serious mental illness	An evidence-based practice first developed to reduce relapse and rehospitalizations among people with schizophrenia and later tested for use with various other serious mental illnesses. It was also shown to improve outcomes for caregivers across multiple dimensions of well-being (Sin & Norman, 2013). It is delivered by mental health professionals. Caregivers learn about the illness; learn, practice, and apply problem-solving skills; and provide one another peer support.
NAMI Family-to-Family Education Program	Family, significant others, and friends of people with mental health conditions	An 8-week evidence-based program with presentations, discussions, and interactive exercises taught by NAMI-trained family members that significantly improves coping and problem-solving abilities.
NAMI Homefront Education Program (Haselden et al., 2019)	Family, friends, and significant others of military service members and veterans with mental health conditions	A 6-week adaptation of NAMI Family-to-Family Education Program.
U.S. Department of Veterans Affairs, Caregiver Support Program	Family caregivers of our nation's veterans	Aims to promote the health and well-being of caregivers through education, resources, support, and services; offers services including skills training, coaching, telephone support, online programs, individual counseling, respite care, peer support mentoring, and a monthly stipend.
<b>Supports for Facilitating Care Recipient's Treatment</b>		
Community Reinforcement and Family Training	Concerned significant others of people using substances	Evidence-based training to change the way people interact with loved ones in order to motivate the person using substances to address their substance use. It also helps family members understand why people misuse substances, develop new skills to cope with old problems, ensure their personal safety, and practice self-care during difficult times.
Listen, Empathize, Agree, Partner	Family members (and others) of people with serious mental illness	An evidence-based communication program to help people improve their relationships with loved ones in ways that can effectively lead the person with mental illness into treatment. Data suggest it has positive effects for the affected person and the relative.*
Psychiatric Advance Directives	People with behavioral health disorders	Legal tools similar to living wills and other medical advance planning documents used in palliative care. They can help reduce caregiver concerns about potential crises by clearly enumerating, beforehand, the care recipient's wishes for treatment during a crisis. They protect the care recipient's autonomy and ability to direct their own care while empowering families to play a role (SAMHSA, 2019).



Table 1 (continued)

Program or Intervention	Targeted Group	Description
Wellness Recovery Action Plan (WRAP) and Family WRAP	Family members of people with mental illness	WRAP is an evidence-based framework for developing effective approaches to overcoming distressing symptoms and unhelpful behavior patterns associated with behavioral health disorders. WRAP initially was developed for people with mental illness, but it has since been adapted to meet the needs of the entire family (Copeland, 2013). WRAP has also been promoted as a crisis planning tool that can help alleviate caregiver stress by outlining clear steps families can take should a crisis arise.  Family WRAP is designed to help each family member contribute to plans that the family will use to improve day-to-day interactions, meet daily challenges, and promote mutual cooperation. Caregivers can also develop their own individual WRAPs for addressing caregiving challenges.

\* Paillot, C. et al. "Double Blind, Randomized, Controlled Study of [LEAP] a Psychotherapy Designed to Improve Motivation for Change, Insight into Schizophrenia and Adherence to Medication." *Schizophrenia Bulletin*, 2009, 35 (suppl 1): 343.

While not specific to caregivers, recent national initiatives to implement coordinated specialty care for first-episode psychosis (Heinssen et al., 2014) and support Certified Community Behavioral Health Clinics (SAMHSA, 2023b) explicitly emphasize the importance of families' involvement in care recipient assessment and treatment planning and provision of family supports.

*"What we really crave is some sense of normalcy even if it's only for an hour... I want to take my mind away from serious mental illness for a while and be with folks who don't have to worry about it because it doesn't affect them. I want to be with that group of people every so often, and that restores a sense of normalcy for me."*

— TEP member

Panelists identified a few interventions that focus on supporting the overall well-being of caregivers. One panelist touted the benefits of programming that provides recreational outlets, such as a virtual art therapy and community arts engagement pilot program that she participated in. Although the program was not specifically designed for caregivers, many caregivers attended the group, about half of whom were caregivers of adults with serious mental illness. She called it "one of the most valuable things I've done in terms of self-care," explaining that it helped "get me out of my own head for a while." There are many

broader caregiver support programs that can benefit behavioral health caregivers, including mindfulness exercises, virtual technologies and applications, and classes on caregiving (Casarez et al., 2019; Ploeg et al., 2017; Renati et al., 2022).

## OPPORTUNITIES TO ADDRESS GAPS IN CAREGIVER SERVICES

Panelists suggested numerous opportunities for policymakers to address gaps in behavioral health caregiver supports that echo the recommendations from the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC, 2017). Panelists also suggested considering how recommendations from the 2022 National Strategy to Support Family Caregivers (ACL, 2023) might be leveraged to support behavioral health caregivers.

## **Opportunities to support caregivers regarding their concerns about care recipients**

When asked which policies would have been most helpful to them as a caregiver, mental health caregivers cited policies that would increase access to care and care coordination, such as enforcing behavioral health parity and providing care navigation services through insurance (AARP & NAC, 2016). They also prioritized ensuring availability of the full continuum of care for behavioral health conditions. This includes eliminating the exclusion of people misusing substances from many crisis, inpatient, and rehabilitation services. Certain sectors are making progress in addressing such exclusion. For example, Centers for Medicare & Medicaid Services (CMS) has released new guidelines for mobile crisis services (CMS, 2021). Caregiver advocacy organizations also often focus on policies that could improve services for care recipients (AARP & NAC, 2020; NAC, 2016), such as expansion of health care coverage for people with behavioral health disorders through Medicaid and other insurance options. Panelists cited particular aspects of Medicaid and private insurance that suggest opportunities for policy improvements: (1) because of low reimbursement rates and payment delays, providers often do not accept Medicaid or other types of insurance, so finding substance use treatment facilities that take particular types of insurance can be especially difficult; (2) coverage might be limited, so the full range of services needed is not adequately funded, and private insurance coverage is usually not as robust as Medicaid; (3) providing behavioral health services is not financially viable for some providers because of billing problems, causing them to shut down and leave many communities without services.

*“For... other illnesses, like... cancer..., [providers automatically think], ‘We want your natural supports to be involved and we want them to get support.’ And I think there should be more of an automatic sense of, ‘The family [of a person with a behavioral health condition] should get family support.’”*

— TEP member

In addition to providing support for caregivers in addressing the immediate needs of care recipients, panelists said caregivers require assistance in planning for the future. For example, one panelist highlighted a group residence program for older adults with behavioral health conditions. Knowing that a loved one could gain access to this type of program as an older adult could bring comfort to parent caregivers who worked their whole lives to support their child and fear what will happen when they pass away.

*“Legal assistance is expensive, you need a lot of help to do a power of attorney and advanced power of attorney for health care or finances, or to establish guardianship. Legal assistance needs to be made available to caregivers for future planning, for estate planning, for what’s going to happen when I’m not here anymore, or I physically can’t do this anymore.”*

— TEP member

Panelists also suggested that caregivers would benefit from initiatives that develop, mandate, and work with teaching hospitals and medical schools to ensure that all providers (not just of behavioral health care) receive regular continuing education or professional development training about serious mental illness and substance use disorder and their implications for effective treatment and communication approaches.

## **Opportunities to improve caregiver information and education**

Sharing more educational resources with family members and caregivers could improve both caregiver and care recipient outcomes. Panelists recommended that direct education and training topics include system navigation and information about services and supports such as short-term respite, one-to-one support, day programs, and residential services; clinical skills, such as cognitive behavioral techniques, de-escalation, and how to support coping strategies; symptom monitoring and how to identify a psychotic episode; strategies to involve family members and loved ones when a person with serious mental illness is in crisis and unable to make their own decisions, including use of psychiatric advance directives; and safety concerns (Cheng et al., 2020; ISMICC, 2017; NAC, 2016; National Family Support Technical Assistance Center, n.d.). One panelist

suggested more widely using NAMI’s Family-to-Family Education Program to educate families about how they can help themselves and their family members, particularly in rural communities.

Communication between providers and family members poses a major challenge. A panelist described health care providers’ prevailing belief that they could not speak to the caregiver without a signed disclosure agreement form from the care recipient but noted that, most often, the form is not even presented to the care recipient, so the default is to have no signature and no caregiver communication. Panelists emphasized the need to improve communications between providers and caregivers, prioritizing the participation of caregivers in treatment whenever possible. ISMICC (2017) also recommended educating both providers and caregivers about HIPAA, substance use disorder confidentiality regulations (42 CFR Part 2), and other privacy laws in the context of psychiatric care, noting the need for clarification and guidance regarding the value of communication with family members and caregivers. Recently, the U.S. Department of Health and Human Services has responded to this need by providing more information regarding HIPAA, including responses to frequently asked questions (Office of Civil Rights, 2024).

### ***Opportunities to support caregiver well-being***

Panelists felt strongly that behavioral health caregivers should automatically receive family support—even if it is just a referral to a family support group—as caregivers for people with other illnesses, such as cancer, often do. They suggested providers should automatically provide information resources to families and even have a counselor for families to talk to available on site, such as in the domestic and sexual violence field. Support should be readily available and seen as part of the overall care people receive when they have a behavioral health disorder. One panelist suggested the need for virtual caregiver support since the COVID-19 pandemic widely familiarized people with the use of virtual technologies such as Zoom. Panelists also agreed that respite care, which exists more for other conditions, should be much more widely available for behavioral health caregivers.

*“We’re... leaving a huge amount of care and love on the table because we’re doing this all wrong.”*

— TEP member

Panelists emphasized the need for sustainable funding for caregiver supports. A variety of mechanisms can and are being used by state Medicaid agencies to support training, services, and direct payment for family caregivers (Kaye & Teshale, 2020), but the extent to which these mechanisms currently support behavioral health caregivers is unknown. Panelists noted the need to establish a clear service definition and provider competencies to enable Medicaid payment for family peer support specialists.

Peer support can be a valuable resource for both care recipients and caregivers; however, coverage of peer support by Medicaid varies by state. In those states where peer support is a covered service, reimbursement rates and limits on allowable services also vary, and they may impede the use benefit of these services (Kaiser Family Foundation, 2022). One panelist said that in her state family peer support is billed to Medicaid at a 15-minute unit rate (i.e., each 15-minute increment of peer support is a separately billable unit). She said the administrative burden in trying to deliver the service and document it appropriately is significant, and the rate does not cover the cost of the service. Additionally, states may place caps on the number of units of peer support care allowable within a day or year (Kaiser Family Foundation, 2022). Another panelist explained that if someone were in crisis, the 15-minute incremental unit rate may only allow the family peer support specialist to arrange for crisis pick-up before leaving and checking on them the next day, depending on state and other payor policies. In contrast, a daily rate can allow the specialist to go to the hospital with the person in crisis, sit in the waiting room with their parents, and go in with them to talk to the doctors. Peers can be included in bundled rates developed for certain services that are not billed on an incremental basis (GAO, 2020).

Other potential funding sources for family caregiver supports are available outside of Medicaid, such as SAMHSA-administered block grants and state general funds. One panelist suggested that the Federal Government could provide community-level funds specifically designated to support behavioral health caregivers through peer support and evidence-based models, as it does for caregivers of older adults through the Older Americans Act.

### ***Opportunities to support the financial well-being of caregivers***

Panelists endorsed expanding family leave policies and promoting recovery and behavioral health-friendly workplaces to afford working caregivers the time they need for caregiver responsibilities without risking their jobs. One panelist suggested establishing a third-party verification system for family leave requests to support use by caregivers concerned about confidentiality and disclosing their loved one's diagnosis to their employer, for example, in smaller businesses. Improved access under the Family and Medical Leave Act could also be a tool to support caregivers of persons with behavioral health conditions, as employees are currently only eligible for leave under the Act if they have worked for their employer at least 12 months, worked for at least 1,250 hours over the past 12 months, and work at a location where the company employs 50 or more employees within 75 miles.

Caregivers would also benefit from their caregiving being treated as paid work. If the care recipient is a Medicaid beneficiary, family members or others can be paid for their caregiving as "personal care attendants" in some states under certain circumstances (American Council on Aging, 2023). As another option, one panelist suggested examining how the stipends paid to caregivers under the U.S. Department of Veterans Affairs' Caregiver Support Program are funded as a potential model for providing stipends to behavioral health caregivers of non-veterans. Another panelist suggested having the Social Security Administration provide credits for the time family members and others spend as caregivers at the same rate that others are being paid for similar services. This would give caregivers going into retirement something in their Social Security record to fall back on to hedge against poverty.

## **OPPORTUNITIES TO FILL GAPS IN CAREGIVER RESEARCH**

The previous sections highlighted existing interventions and opportunities for improving how caregivers are supported. Panelists noted, however, that although evidence-based interventions exist, they are not widespread and might not be appropriate for specific communities. In addition, one panelist asserted that many interventions that are available and helpful to caregivers may not have been studied, lowering their chances for wider implementation. Overall, the predominance of the professional literature on caregivers pertains to those caring for people with cancer or dementia, with a sizable gap in attention to behavioral health caregivers. Literature is lacking on rural, young adult, and gender diverse caregivers as well as on specific racial, ethnic, and cultural groups and the intersectionality of these groups. Panelists also described the current literature and policy context as lacking complexity regarding care recipient and caregiver transitions across the lifespan. To support adoption of existing programs and interventions that could benefit behavioral health caregivers, the panel recommended more research on these interventions and on tailoring them for specific communities. It also recommended that funding and resources be allocated to collect data for evaluation of program efficacy to inform future interventions.

## **CONCLUSION**

Caregivers of people with behavioral health disorders often provide emotional, financial, logistical, legal, and clinical support to their loved one for years. While all types of caregiving have associated stresses and negative health outcomes, these experiences are often more strenuous and long-lasting among behavioral health caregivers. We saw this in the available literature and heard it from the technical experts. Their loved one's

increased risk of homelessness, incarceration, victimization, and death help to explain why behavioral health caregiving poses such unique challenges. These caregivers express a profound sense of desperation, fear, and helplessness, waiting for the next crisis, often without social support due to real or perceived stigma. Greater availability of quality behavioral health care, care coordination, and information sharing can all help to alleviate some of these difficulties, benefitting caregiver and loved one alike.

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