



# Supporting Family Caregiver Engagement in Behavioral Health Systems and Treatment

## The Challenge

Family caregivers often play an important role for individuals with mental health and substance use needs by helping support treatment plans, monitor changes, and navigate services (see [SAMHSA's Working Definition of Recovery](#)). However, caregiver involvement in behavioral health treatment is not consistently defined or supported. As a result, caregivers are often brought in informally or late in treatment, limiting opportunities to support continuity, engagement, recovery, and crisis prevention.

Engagement should reflect the individual's preferences about who is involved in their care and what information may be shared. States have opportunities to clarify when and how caregivers can appropriately participate in treatment, consistent with individual choice and consent.

## Strategy 1: Identify and Engage Caregivers within State Behavioral Health Systems

Caregivers frequently interact with state behavioral health systems but are not consistently identified, counted, or engaged in system design. Without intentional identification, states can miss opportunities to incorporate caregiver perspectives into program development, financing decisions, and accountability structures. Formal engagement can inform policy priorities, service design, and funding strategies before caregiver strain contributes to avoidable crisis utilization.

### State actions to consider include:

- Offer structured opportunities for individuals to name a caregiver or support person.
- Encourage [caregiver identification](#) and assessment within Medicaid, home and community-based services (HCBS), or behavioral health intake and care planning processes by adding a question.

- Use caregiver assessments to identify stress and burnout risk, and connect caregivers to respite and behavioral health supports.
- Engage caregivers through behavioral health planning councils, advisory committees, and other partner engagement structures.

**Promising examples include:**

- [Community Behavioral Health Services Block Grants](#), which require states to engage individuals and families in system planning, creating opportunities to elevate caregiver perspectives.
- [North Carolina’s State Consumer and Family Advisory Committee](#), which provides caregiver and family input into state behavioral health policy.

## Strategy 2: Clarify Caregiver Roles through Privacy, Consent, and Care Planning Tools

Caregivers often support individuals with behavioral health treatment goals, yet unclear privacy and consent policies can limit their ability to communicate with providers or participate in care planning – even when individuals want their involvement. Clear parameters help caregivers support stability, recovery, and continuity of care. These tools allow individuals to proactively decide when caregiver involvement is helpful rather than making decisions during a crisis.

**State actions to consider include:**

- Issue plain-language guidance clarifying how the Health Insurance Portability and Accountability Act (HIPAA) and [42 CFR Part 2](#) permit caregiver involvement with appropriate consent.
- Create a cross-system support-person authorization that travels with the individual across crisis and treatment settings to enable safe post-crisis follow-up.
- Encourage use of [psychiatric advance directives](#), and align state policies with updated 42 CFR Part 2 requirements.

**Promising examples include:**

- Approximately [25 states](#) authorize psychiatric advance directives, allowing individuals to clarify preferred supports and caregiver involvement before a behavioral health crisis.
- The New York State Office of Mental Health has issued [guidance](#) and shared [educational materials](#) on engaging families and caregivers in behavioral health treatment while complying with HIPAA and state confidentiality laws.

## Strategy 3: Expand Access to Behavioral Health Practices That Involve Caregivers in Treatment

Behavioral health services are typically designed to support individual treatment and self-management, while family caregivers frequently play an important role in day-to-day care. States may use contract requirements, guidance, program design, and [public-private partnerships](#) to advance [evidence-based behavioral health practices](#) that engage caregivers, such as family-based interventions, skills training, and structured education. These approaches can strengthen treatment engagement, support recovery, and improve outcomes for both individuals and their caregivers.

### State actions to consider include:

- Encourage providers and managed care plans to incorporate caregiver engagement into care planning, treatment goals, and follow-up, when consistent with individual preferences and consent.
- Leverage tele-behavioral health and community-based delivery models to reduce access barriers.
- Support adoption of evidence-based family and caregiver behavioral health programs, such as family-based therapy, skills training, consumer-centered family consultation, and [family peer specialists](#).
- Cover or finance behavioral health respite services through Medicaid, HCBS waivers, or state-funded behavioral health programs to reduce caregiver stress and prevent crisis escalation.

### Promising examples include:

- Washington State funds the [Center of Parent Excellence project](#), providing one-on-one and peer-based support to parents and caregivers of youth with behavioral health needs to strengthen system navigation, engagement in treatment, and family stability.
- [Illinois](#) and [New Jersey](#) invest in the [NAMI Family-to-Family](#) program through state funding and administrative authority to support statewide caregiver education and peer support.
- States can look to federal models such as the Department of Veteran Affairs (VA) [Caregiver Support Program](#), which integrates respite and clinical mental health services for caregivers of eligible and covered veterans enrolled in the VA and illustrates integration of caregiver services within an existing delivery system.
- Through [OhioRISE](#), Ohio includes [behavioral health respite](#) as a covered service for eligible youth, providing short-term relief to primary caregivers to help sustain family placement and reduce crisis-driven transitions.

## Looking Ahead

Clarifying caregiver roles in behavioral health treatment can support communication across crisis, outpatient, and care management settings; support more consistent care outside clinical settings; and reduce avoidable crisis system utilization. States can advance this work by using existing behavioral health authorities to promote caregiver-inclusive practices and provide clearer guidance for providers, individuals, and families.