Treatment Advocacy Center

September 2026

HIPAA and Care Partner Engagement

Policy Statement:

TAC supports changes in law, policy, and provider training to encourage engagement between individuals with SMI, providers, families, and care partners.

A care partner can be any responsible adult with an important relationship to a person with SMI who provides day-to-day support and care. While not all family members are care partners, we refer to both care partners and families throughout this text in recognition of the important role that families can play in facilitating access to care, even when they are not involved with day-to-day caregiving. TAC acknowledges that not all families of origin are supportive, and that "community as family" is an important part of recovery for many individuals with SMI.

Summary:

Despite extensive evidence demonstrating improved outcomes for people with SMI when providers engage with family and others who offer consistent support,[i] care partners are often blocked from collaborating with, receiving information from, or even sharing information with their loved one's care team. Patient confidentiality is often cited as the reason for lack of communication.[ii] Privacy rules within the Health Insurance Portability and Accountability Act (HIPAA) allow for routine and often critical communications but allowances specific to mental health are poorly understood and too rarely utilized. Reforming HIPAA to clearly articulate professional ethical standards for engagement with care partners can encourage best-practice treatment for people with SMI conditions. Training is needed to shift habits of practice.

Background:

HIPAA allows communication with care partners in many different situations.

HIPAA was passed in 1996 to protect sensitive health information, particularly with risks related to storage and exchange of electronic records. To that end, HIPAA requires

accountability from providers to protect the confidentiality of patient records. From the start, HIPAA has also supported transfer of medical records between providers and encouraged information sharing with care partners to ensure continuity of care for patient well-being and safety.

In recognition of unique challenges related to mental health, the U.S. Department of Health and Human Services, within its Office for Civil Rights, clarifies exceptions to HIPAA's privacy rule.[iii] Under HIPAA, providers are permitted to share information with care partners under many different circumstances, including:

- When the care partner is a personal representative.
- When the patient signs a release of information (ROI), specifically permitting disclosure to a care partner.
- When the patient has been asked and does not object to care partner involvement, with or without a formal ROI.
- To lessen risk of harm to the health or safety of the patient or others.
- When the patient has had care partners involved in their care or payment for their care in the past and does not presently object.
- When the patient is unable to agree to or object to involvement from care partners due to symptom severity and incapacity.

Care partners often have critical knowledge about the historical and current medical needs of their loved ones, who may not accurately describe their treatment history due to acute psychotic symptoms or memory impairments associated with their illnesses,[iv] and no aspect of HIPAA prohibits providers from receiving collateral health information from care partners. HIPAA law supports the communication of this health information by offering providers the option to keep the source of information confidential if disclosure could compromise the relationship between the patient and their care partner.[v]

Training and policy changes are needed.

To close the research-practice gap on care partner engagement, providers must be given structured training to support shifts in practice. Provider training should emphasize how to leverage a care partner's deep knowledge about a patient's psychiatric, behavioral, and medical history,[vi] including by requesting critical historical information whenever possible.

Training needs to include best practice protocols for communicating when family relationships are complicated. In addition to providing structured training, administrators can support care partner engagement through policies that allocate sufficient time for care partner

engagement and ensure providers are compensated for time spent with care partners. Recognizing that SMI is a serious medical condition, training on information sharing in the behavioral health field should also align with best practice standards for information sharing used across the rest of the medical field.

Recommended actions:

Reform HIPAA to require communication with known care partners when there is a documented safety concern and when a patient lacks the ability to make informed medical decisions, determined through a required and standardized evaluation process.

By requiring instead of just allowing communication under these conditions, HIPAA can be used to ensure that providers align treatment with care partner engagement as a best practice for care while still protecting patient privacy. John's Law in Arizona[vii] provides one example of a legal requirement to solicit and consider information from care partners in certain emergency situations. Federal law currently allows but does not require providers to share treatment information unless the care partner is a personal representative.[viii] Providers should retain professional discretion to withhold information when documented evidence clearly demonstrates a risk of harm to the patient if information is shared. However, when information sharing is permissible under HIPAA law, non-disclosure should be the rare exception, and documentation should be required to justify a departure from information exchange as a standardized best practice.

Normalize care partner engagement through structured training and clear policies.

Care partner engagement and family-focused interventions have been demonstrated to improve outcomes for people with SMI,[ix] and most people with SMI express a desire for their care partners to be involved.[x] Multiple international policies and guidelines also recognize the importance of care partner engagement for the treatment of SMI.[xi] To end blanket non-disclosure policies that put providers, patients, and care partners in harm's way, provider agencies must articulate ethical and professional standards for communication with care partners. Providers must also be supported in engaging with care partners through structured training programs, allocation of sufficient time to facilitate productive engagement, and funding for time spent engaging with care partners.

References

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