



Schizophrenia
& Psychosis
Action Alliance

Position Statement

HIPAA Should Not Freeze Family Members out of Treatment Decisions

HIPAA's strict privacy protections are critical safeguards for sensitive personal health information.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created a national standard for the protection of certain types of health care information. The U.S. Department of Health and Human Services issued a "Privacy Rule" in 2002 to implement the requirements of HIPAA. The Privacy Rule limits the circumstances in which individually identifiable health information can be used and disclosed by covered entities including health care insurers, providers and clearinghouses.

HIPAA grants individuals control over their health information and shields their medical records from unauthorized access. These protective measures prevent the misinterpretation of medical information that could cause undue stress or family conflict, and support the patient's autonomy and confidence in managing their own healthcare. Such protections also are designed to foster trust in patient-provider relationships and encourage individuals to seek necessary care without fear of discrimination.

Although healthcare professionals typically need a patient's permission to share their health details with others, there are important exceptions to this rule.

Typically, health information can only be shared if a patient signs a consent to release personally identifiable health information to a specific party. However, even without consent, providers can share protected health information when it is deemed necessary to prevent a serious and imminent threat to the patient's safety and health. Additionally, if a patient is incapacitated or otherwise unable to provide consent, healthcare providers may use or disclose information for treatment purposes, as necessary, if doing so is in the best interests of the patient.

These exceptions are critical and especially relevant to the care of people with schizophrenia for two reasons:

1. Many people with schizophrenia experience a neurological symptom called anosognosia, in which they do not understand that they have an illness. This can render them unable to make sound healthcare decisions on their own behalf.
2. Family members and other caregivers often play a pivotal role in providing care for people with schizophrenia, including supporting treatment adherence, housing and

finances. This can make it critical for caregivers to have access to medical information when those with schizophrenia are unable to make informed decisions about their care.

Tragically, healthcare providers rarely use allowable HIPAA exceptions for people with schizophrenia, leading to disastrous consequences.

Misinterpretations of HIPAA and/or fear of lawsuits can lead to an overcautious approach in which healthcare providers refuse to share information with caregivers, even when it could be critical for optimal patient care. In some cases, this results in terrible consequences for both patients and their families, including lower-quality treatment, deteriorating physical health, increased risk of harm to the patient or others, emotional distress and in the most harrowing cases, homelessness and suicide.¹⁻³ **The intention behind HIPAA was not to obstruct care coordination and endanger patients, or to prevent families from getting information they need to care for their loved ones.**

When refusal to provide (or accept) critical health information about a patient results in worsening illness, homelessness or even death, HIPAA has been used inappropriately and has harmed those it is meant to protect. **In certain circumstances, the most medically beneficial and compassionate move may be to share information with family members/caregivers, even without consent from the person with schizophrenia.**

In 2016, on a bipartisan basis, the House Energy & Commerce Committee approved the Helping Families in Mental Health Crisis Act (HR 2446, House Report 114-667). Title IV, Section 401(d) contains the following provision:

*“It is the sense of the Congress that, for the sake of the health and safety of persons with serious mental illness, more clarity is needed surrounding the existing HIPAA privacy rule....to **permit health care professionals to communicate**, when necessary, with responsible known caregivers of such persons, the limited, appropriate, **protected health information of such persons in order to facilitate treatment**, but not including psychotherapy notes.”*

However, updated HIPAA regulations, additional guidance in the form of Frequently Asked Questions that was published by the HHS Office of Civil Rights (OCR), and clinician training efforts have failed to break down the dangerous barriers that healthcare providers continue to mistakenly create.

Call to Action

S&PAA supports funding from the relevant federal, state and/or local resources to accomplish the following aims:

1. **Creation of direct statutory amendments to HIPAA.** Specifically, we call on federal lawmakers to carve out an exception that explicitly authorizes the sharing of protected health information necessary to provide care to the family members and caregivers of people with severe mental illnesses. This should only be done when a clinician certifies – via documentation in the medical record – that symptoms such as anosognosia or other

aspects of psychosis impair the patient's capacity to make an informed choice with regard to the sharing of medical data.

2. **Research to inform educational efforts.** Resources should be directed to study provider perspectives on HIPAA, identify barriers to sharing information and explore concerns about potential liabilities. This research will inform targeted educational initiatives to bridge knowledge gaps among a spectrum of providers. This clarity also is essential for enabling family members to effectively support their loved ones.

References

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2. Gold J. *Privacy Law Frustrates Parents of Mentally Ill Adult Children*. National Public Radio; 2014. <https://www.npr.org/sections/health-shots/2014/06/04/318765929/privacy-law-frustrates-parents-of-mentally-ill-adult-children>
3. Earley P. *Parents Successfully Sue Hospital after Son's Suicide: Doctors Agree to Listen & Not Hide behind HIPAA*.; 2023. https://www.petearley.com/2023/12/15/parents-successfully-sue-hospital-after-sons-suicide-doctors-agree-to-listen-not-hide-behind-hipaa/?fbclid=IwAR3YOv35BwM7oPs1NzxiF1ZbP7LwSukaGvCYubL1X9Shq31_7iqkbR2raEo