Care Partner Engagement

Is there evidence that family involvement improves outcomes?

Yes. According to research from the American Psychiatric Association, "Individuals with SMI have better treatment outcomes when a family member or other support person is involved in their care." The same research study states: "Attempting to contact and involve a family member should be part of standard care for mental health inpatients."

What is meant by the term care partner?

A care partner is someone who provides ongoing support to an individual with SMI. This person may also help with decision making. A care partner can be from someone's family of origin or another important person in their life.

What do families want providers to know?

Families want to collaborate, especially when sharing mental health history. Families want stakeholders throughout the system to know what the data show; outcomes improve with our involvement. The historical blaming of families must end. Families want to partner with the system to prevent a crisis, not watch and wait for a crisis to finally force the system to respond. Families are frequently the ones most invested and provide support and resources without any formal financial support for care.

Does SMI cause violence?

Most individuals with SMI are not dangerous, and most violent acts are committed by individuals who don't have SMI. Those who successfully engage in treatment are not more violent. However, it's false to claim that SMI is never dangerous. Untreated SMI contributes to aggression and violence. In about two-thirds of cases, the violence is self-directed. Other forms of violence most frequently impact care partners.

Why does HIPAA keep getting in the way?

The Health Insurance Portability and Accountability Act (HIPAA) was implemented in 1996 to protect sensitive health information and records. The law requires providers to keep medical information confidential unless they are sharing it with other providers for continuity of care. Misunderstandings about HIPAA have led to non-disclosure policies that often block families from supporting loved ones with SMI. The law never blocked families from sharing information, but providers sometimes use HIPAA as an explanation to block all forms of communication. Advocacy is needed to improve understanding and to promote better training about what HIPAA allows.

Talking points

- Research supports family engagement as an evidence-based way to improve treatment outcomes for individuals with SMI.
- Strict nondisclosure policies are not aligned with science or the law and have to do with resource shortages and unrealistic fears related to HIPAA.
- HIPAA has been misunderstood and does not block all communications between families and providers. Training is needed.
- Untreated or under-treated SMI increases risks for suicide and violence against family members. The way to prevent risk of harm is to provide timely and effective treatment.

Go deeper

- A TAC website article about HIPAA explains what's allowed and what's been misunderstood. Included are links to key federal guidance documents.
- TAC's two-page handout with an infographic built during a national symposium on AOT highlights what families want stakeholders throughout the system to know to improve outcomes for people with SMI.
- Data make clear that most people with SMI caught in the system want loved ones involved. A New York study of inpatients found that 92 percent of them wanted family involved in their care planning.
- Families can encourage providers to engage with them by sharing a concise, fact-based mental health history. TAC's article and fillable form can help.
- Untreated SMI is known to contribute to violence against self (2/3 of cases) and others, particularly family caregivers. TAC provides research data on violence and its linkages to SMI. A specific report, Raising Cain, highlights the increased risk for family homicides when a member has untreated psychosis.