



Depression and Bipolar
Support Alliance

Position / Policy Overview and Recommendation

Position Title:

Personal and Civil Rights: Privacy of Personal Health Information

Position Policy (provide brief description of the recommended position / policy)

DBSA advocates for the right of peers to choose their own paths to mental, emotional and physical wellness while promoting structures and practices that advance whole health and accessible care for everyone. Advancing this DBSA value includes a vision for a society where peers not only have the same freedoms enjoyed by other Americans under the U.S. Constitution, either explicitly or adjudicated by the United States Supreme Court, but also have the autonomy to make their own decisions about how to use and apply those civil and human rights. This paper is one in a series about positions of particular relevance to peers that focus on Supreme Court decisions and federal legislation protecting the rights to:

- live in the community,
- privacy of personal health information, and
- safe gun ownership.

Justification (Explain the need for and the urgency of the position / policy. Attach supporting pages as necessary)

Executive summary of issue

Basic human and civil rights for people living with mood disorders can often conflict with larger societal attitudes. These attitudes can find their genesis in discrimination, often grounded in fear, as a result of being uninformed. As the leading peer-focused organization for people living with mood disorders DBSA has a responsibility to champion the rights of peers through legislative advocacy and thoughtful education and dialogue with those who hold opposing views.

Every individual has a right to an expectation of personal ownership of their personal health information (PHI). This is a constitutional right under the Fifth Amendment—protection against self-incrimination, as well as the Ninth Amendment which protects privacy rights not covered in the first eight amendments. Ownership includes the right to decide with whom that

information is shared. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) guarantees this right of ownership to the individual. This law can often create a hardship endured by loved ones who may be desperate for medical information when the peer is experiencing a mental health crisis. For example, in a 2014 DBSA survey on Peers and Caregivers Experiences with the Emergency Department, 32% of caregivers responded that they had not been provided opportunity to share a loved one's PHI. Only 20% gave the emergency department good marks for keeping them informed on their loved one's status.

Existing policy around issue

The civil liberty to privacy is embedded in the American identity, as well as the DBSA stated Values and Core Beliefs. Among them is the belief that: *All individuals have the right to direct their own care.* Pivotal to directing one's own care is deciding who does or does not have knowledge about that care.

The DBSA Position Paper, *Stigma and Discrimination*, provides the following call to action regarding discrimination: *"Devoting resources to reduce and eliminate stigma and discrimination for people living with mood disorders is central to the DBSA mission. DBSA calls upon society to examine how it can more sensitively address these issues through its various institutions and media outlets."*

Relevant legislative or regulatory concerns

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides security provisions to safeguard a patient's health information. Title 2 establishes standards for processing electronic healthcare transactions and provides rights to patients about who has access to their PHI. The intent of this section is to limit the use and disclosure of PHI to only those entities or people for whom the patient has expressly given permission. The 2019 HIPAA Omnibus looked to address how mental health information is protected and the ability of doctors and hospitals to coordinate care. As a result, HIPAA now allows PHI to be shared with other health plans or health care entities without patient authorization for case management and care coordination so long as both entities have a relationship with the individual.

Recommended position / policy and call to action

HIPAA supports DBSA's non-discriminatory position that people living with mood disorders have the same rights and protections under the law, regardless of a medical diagnosis. DBSA recognizes these protections can provide a hardship for caregivers and family members who may want to be notified of a loved-one's care or be involved in that individual's care.

HIPAA does not disqualify caregivers from providing medical information about a loved one to a clinician and does not restrict a clinician from accepting and using that information in the treatment of the patient. Additionally, federal law supports a legal instrument which allows caregivers to be involved in a loved one's care: a Psychiatric Advance Directive (PAD).

A PAD is a written document created by an individual outlining how they wish to receive care in the event they are not able to communicate with the clinical care team. Further, it can identify those individuals who can be informed, involved, and even have legal authority to make medical decisions if they are incapacitated. Any facility receiving Medicare or Medicaid reimbursement is required to accept a legally executed PAD.

Using existing education and communication tactics (e-update, DBSA website, chapter communications, advocacy newsletter), DBSA should inform the community about thoughtful and well-reasoned solutions that ensure clinicians are informed about a loved one's PHI and that caregivers are able to participate in a loved one's care, so long as that is the desire of the peer.

DBSA should support, state initiatives that make using PAD's more accessible by encouraging DBSA state organizations and chapters to stay informed on the issue in their state and engage in advocacy activities as applicable.