Substance Use Disorder & Mental Health
Privacy Rights for Individuals and Families

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2:30 PM EST
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- Typed questions/chat
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Step 1: Click "Chat"

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The National Family Support Technical Assistance Center (NFSTAC) is the nation’s first Substance Abuse and Mental Health Services Administration (SAMHSA)-funded Center of Excellence (CoE), and is focused on supporting families and caregivers of children, regardless of their age, who experience serious mental health and/or substance use challenges.

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Funded by SAMHSA, the CoE-PHI develops and disseminates resources, training and technical assistance (TA) for states, healthcare providers, school administrators, individuals and families to improve the understanding and application of, federal privacy laws and regulations; **including FERPA, HIPAA, and 42 CFR Part 2**, when providing and receiving treatment for SUD and mental illness.

*Resources, training, technical assistance, and any other information provided through the CoE-PHI do not constitute legal advice.*
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Presentation Objectives

Identify how federal health privacy laws protect SUD and MH treatment information; especially when the family is involved in care.

Understand how individuals and families can work together in a way that supports recovery and respects the individual’s privacy and choices.

Recognize key points for families to consider when sharing or requesting SUD/MH treatment information.
Poll Question #1

Please rate your level of agreement with the following statement:

"I don't always know what questions to ask providers to ensure that my family can be involved in my care, or so that I can be involved in my family member's care."

a) Strongly agree
b) Agree
c) Somewhat agree
d) Disagree
Confidentiality Overview for Individuals & Families
Why Confidentiality?

• **Privacy is key to recovery**
  - *Everyone should be able to get the help they need, without worrying about who knows it.*
  - *Family members: You have a role to play in helping your loved one get better.*

• **Privacy is the law**
  - *Know the facts about individuals’ privacy rights and accessing confidential care.*
Which Laws Apply?

- Health Insurance Portability & Accountability Act (HIPAA)
- SUD privacy law (42 USC 290dd-2 & 42 CFR Part 2)
- State privacy laws

- **Providers also have an ethical duty of confidentiality and additional professional licensing requirements.**
Today’s discussion will focus on privacy protections under HIPAA.

If you or your loved one receives SUD treatment services from a “Part 2 Program,” additional privacy protections apply.
What Information is Protected?

• HIPAA protects the privacy of a broad range of general health information in any form that can identify an individual and that relates to past, current, or future physical or mental health conditions or healthcare services.
  • Examples: Name, diagnosis, treatment, clinical notes, prescriptions
Sharing Information With Family
Who is “Family”?

Today we are using the word “family” broadly to mean anyone the patient chooses to involve in their caregiving.

“Family” can include, but is not limited to: adult children, parents, siblings, partners and/or friends.
When does HIPAA permit a healthcare provider to share information with family?

- Individual consent
- Individual does not object
- Individual is not available
- Threat of serious harm

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Individual Consent

• HIPAA permits a provider to share any health information as authorized by the individual:
  • Written consent or
  • “Personal representative” under state law

• Pro-Tip: Ask the provider for a release of information (ROI) that authorizes disclosures to preferred family members and make sure to keep a copy.
When does HIPAA permit a healthcare provider to share information with family?

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- Individual does not object
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Individual Does Not Object

• HIPAA permits a provider to share information with family if the patient is present during the disclosure and has an opportunity to object
  • Or if the individual is not present and the provider reasonably infers, based on professional judgment, that the individual does not object

Let’s explore what this looks like through a case study.
Case Study #1

Leo

- Leo is admitted to the hospital for an opioid overdose
- While his sister Emma is visiting him in the hospital, the doctor enters the room to discuss Leo’s recovery and treatment options
- Leo asks Emma to take notes for him
Case Study #1
Leo

What can the doctor share in front of Emma?

a) Nothing: Emma must leave the room because she is not Leo’s parent or child.
b) Nothing: Emma must leave the room because Leo did not sign a consent form authorizing the disclosure.
c) Anything about Leo’s recovery and treatment options, because Leo had an opportunity to object.
d) Anything from Leo’s health history, including information protected by stricter health privacy laws for SUD treatment records and HIV information.
c) Anything about Leo’s recovery and treatment options, because Leo had an opportunity to object.

- Leo had an “opportunity to object” when doctor asked to discuss recovery and treatment options
- Emma’s exact relationship to Leo does not matter; Emma could even be a close friend
- No written consent/authorization is required for disclosure

Practice tip for Leo: Begin a conversation by clarifying what the doctor plans to discuss or by asking for a few minutes alone with the doctor first.
When does HIPAA permit a healthcare provider to share information with family?

- Individual consent
- Individual does not object
- Individual is not available
- Threat of serious harm
Individual is Not Available

- HIPAA permits the provider to share information with family involved in the individual’s care if the individual is not present or lacks capacity, and the provider determines that doing so is in the individual’s best interest.
  - Examples would be when an individual lacks capacity: Unconscious, sedated, severely intoxicated, mental health crisis (in some cases)
When does HIPAA permit a healthcare provider to share information with family?

- Individual consent
- Individual does not object
- Individual is not available
- Threat of serious harm
Threat of Serious Harm

• HIPAA permits the provider to share information with *anyone* in order to prevent or lessen the threat of serious harm to the individual or anyone else.
  • Example: When an individual threatens to harm someone else and/or themselves
When does HIPAA permit a healthcare provider NOT to share information with a personal representative?

- Reasonable belief that disclosure would put the individual at risk
- Professional judgment that disclosure is not in the best interest of the individual
Additional Case Studies & Discussion
Case Study #2
Silvia

- Juan takes his daughter Silvia to St. Elmo’s Treatment Center for inpatient MH treatment
- Juan is Silvia’s primary caregiver and shares information about Silvia’s medical background, medication and providers
- A few days later, St. Elmo’s calls Juan and says, “Silvia is ready for discharge.”
- St. Elmo’s does not provide any further information about Silvia’s current status, medication changes or recommendations for follow-up appointments
What can St. Elmo’s share in front of Juan?

a) Nothing: Juan must pick up his daughter and figure out the next steps on his own because he is not Silvia’s legal guardian.

b) Nothing: Juan must pick up his daughter and figure out the next steps on his own because Silvia did not sign a consent form authorizing the disclosure.

c) Anything about Silvia’s recovery and treatment options, because Juan is her primary caregiver.

d) We need more information to answer this question.
Case Study #2 | Discussion
Juan and Silvia

• What does Juan need to know about HIPAA?
• How can Juan work with St. Elmo’s to better coordinate sharing information about his daughter’s mental health treatment?
Case Study #3

Lola

• Lola, who is 19 years old and in her first year at college, is admitted to inpatient psychiatric care at Green Valley.

• Lola’s parents travel to visit her from out of state.

• Green Valley tells them that Lola does not want to see them and has not consented to sharing any information with them.

• Green Valley won’t let Lola’s parents share information about previous treatments, medications, etc.

• Lola’s parents are upset because they are financially supporting her and she is still on their insurance plan.
Case Study #3  
Lola

What can the parents do about the situation?

a) Nothing: Lola is an adult and has the right to refuse to see her parents or disclose any info to them.

b) They can speak with the staff and share information with them from their perspective, but they cannot see their daughter or discuss her treatment without her consent.

c) They can demand to see their daughter and discuss her treatment because they financially support her, and their insurance is paying for the facility.
Case Study #3 | Discussion

Lola

• What do Lola’s parents need to know about HIPAA?
• How can Lola’s parents work with Green Valley to support Lola’s treatment and recovery?
Case Study #4

Xander

• Xander, who is 24 years old, is admitted to the ED, unconscious due to a drug overdose and an exam reveals that Xander is pregnant

• Their father, Bill, arrives at the hospital and asks for information about Xander’s status

• A nurse tells Bill that Xander is being treated for a drug overdose and further examination revealed that Xander is pregnant

• Xander is upset to learn that the hospital shared this information with their father
What are Xander’s options?

a) Nothing: The nurse had the right to tell Xander’s father about the situation because Xander took illegal drugs.

b) Nothing: The nurse had the right to tell Xander’s father about the situation because Xander’s drug use was harming their unborn child.

c) File a complaint because the nurse released confidential information without their consent.
Case Study #4 | Discussion

Xander

- What do Xander and Bill need to know about HIPAA?
- Would it matter if Xander were a minor?
Case Study #5

Frank

- Frank is 18 with a dual diagnosis of MH & DD, still in HS with an IEP & living at home with parents.
- Due to isolation and lack of services due to COVID, he has been having frequent outbursts, hitting his mother, and engaging in self-injurious behavior.
- In a session with the behaviorist, Frank threatens to run away and kill himself.
- When the behaviorist speaks with him about wanting to discuss his care with his parents, he becomes enraged and shouts “No! No!” over and over.
What can Frank’s parents discuss with the behaviorist?

a) Nothing: Frank is verbally refusing to have the behaviorist speak with his parents.

b) Anything about Frank’s care, because he lives with them and they pay for it.

c) Anything about Frank’s care because he has a cognitive disability.

d) Information about his threats to run away and kill himself because the provider believes it is necessary to prevent a risk of serious harm to Frank.
Case Study #5 | Discussion

Frank

• What do Frank’s parents need to know about HIPAA?
• Does it matter whether Frank is a minor?
• How can Frank’s parents work with the behaviorist to support Frank’s treatment?
Key Points

- Identify individual’s preferred role for family.
- Communicate with providers early and often.
- Family members can always share information with providers to promote individual care and treatment.
- There are times when family and caregivers are allowed by law to receive information about their loved one’s care/circumstances.
- Providers have some discretion about when to share and when not to share with family, based on their professional judgment.
UNDERSTANDING HIPAA: What Parents Need to Know About Privacy & Their Adult Child’s Health Information

When does HIPAA allow healthcare providers to disclose protected health information to parents involved in their adult child’s care?

**WHAT YOU NEED TO KNOW**

- The Health Insurance Portability and Accountability Act of 1996 ("HIPAA") is a federal law that sets national privacy standards limiting the use and disclosure of individuals’ health information (known as “protected health information” or “PHI”).

**KEY POINT**
As your child grows into adulthood, both your rights and the rights of your child under HIPAA change.
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