

Understanding Data Privacy

Rules and Resources for Obtaining
Mental Health Care Information

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ADULTS



National Alliance on Mental Illness

MINNESOTA

Phone: 1-651-645-2948

Toll Free: 1-888-NAMI-HELPS

www.namimn.org



NAMI Minnesota champions justice, dignity, and respect for all people affected by mental illnesses. Through education, support, and advocacy we strive to effect positive changes in the mental health system and increase the public and professional understanding of mental illnesses.

UNDERSTANDING DATA PRIVACY

Rules and Resources for Obtaining Mental Health Care Information

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INTRODUCTION

When someone experiences a serious illness, they often turn to family members for help and support. Families offer practical help - such as housekeeping, making meals, or providing transportation - and provide advice, knowledge and encouragement. For many individuals and families whose serious illness is a mental illness, obtaining that support and advocating for a loved one can be extremely difficult due to the interpretation of data practices laws.

Providers often mistakenly believe that these laws prevent them from speaking or listening to families of people living with a mental illness. There are two major laws. One is HIPAA (Health Insurance Portability and Accountability Act), which is a federal law. The other is the Minnesota Data Practices Act.

This booklet explains the basics of both laws. Families are encouraged to distribute this booklet to mental health professionals so that they have information about these laws. Please note that the laws governing substance use disorders are different. ■

Privacy Release

Under Minnesota and Federal laws, health care providers need permission to share health or mental health care information with others. Families of people living with a mental illness will often say that they feel providers are far more restrictive when sharing mental health information.

Especially when someone is first hospitalized, individuals may not be willing to sign a privacy release. Family members can request that hospital staff ask the individual again on another day if they would sign the form. Providers are also allowed to share information when the patient is in the same room with the family members and verbally agrees to information being shared. Even if they won't sign a release, families can share relevant information with providers. If families do share information, know that the provider may tell the individual who shared the information with them. Families must be proactive, but remember that to be an effective advocate one must be clear, succinct and calm.

If the person with a mental illness signs a regular privacy release, the provider can release all the records. One exception to the type of information that may be released is psychotherapy notes. These notes are considered primarily for the personal use by the treating professional and are kept separately from the rest of the person's medical record. Some providers have a privacy release that states exactly what informa-

tion can be provided. Some providers have a privacy release that states exactly what information can be provided.

Minnesota Law

Under Minnesota Health Records a person's health records cannot be released without:

- ▶ A signed and dated consent from the patient or the patient's legally authorized representative authorizing the release;
- ▶ Specific authorization in law; or
- ▶ A representation from a provider that holds a signed and dated consent from the patient authorizing the release.

This law does not prohibit the release of health records during a medical emergency when the provider is unable to obtain the patient's consent due to the patient's condition or the nature of the medical emergency; to other providers within related health care entities when necessary for the current treatment of the patient; or under certain circumstances to a health care facility. In cases where a provider releases health records without patient consent, the release must be documented in the patient's health record.

FAMILY INVOLVEMENT LAW

Purpose of Family Involvement Law

Individuals are often unwilling to grant their family members full access to their medical records. Concerned that there was an "all or nothing" approach for individuals and families, NAMI Minnesota successfully advocated for a change in the Data Practices law that allows limited but important information to be released to families. The bill was called the "Family Involvement Law." The law created an alternative to signing a full privacy release to access medical records.

Minnesota's Family Involvement Law expands access to mental health care information by allowing caretakers to access mental health care information that will help them to care and advocate for a person with a mental illness. This law was passed in 2006, Chapter 253. This section of the law was rewritten in 2007 and can now be found in Minnesota Statutes, section 144.294 subdivision 3 (Chapter 147).

Mental health professionals are encouraged to suggest this alternative to individuals who are reluctant to sign a privacy release. Involving families can be very helpful since they may know the treatment history and current symptoms and may be responsible for transportation, follow-up and support after a hospitalization.

Requesting Health Information About a Person with a Mental Illness

Any person, whom we will call a caregiver, can request mental health information about a person with a mental illness IF they:

- ▶ live with the person with a mental illness
- ▶ care or help obtain care for the person with a mental illness
- ▶ are *directly* involved with monitoring the well-being of the person with a mental illness

It is important to note that the caregiver's involvement must be verified by someone such as a mental health or health care provider, the individual's doctor, or anyone other than the caregiver putting in the request.

Definition of a provider:

- ▶ person who gives health care services
- ▶ home care provider
- ▶ health care facility
- ▶ physician's assistant
- ▶ unlicensed mental health practitioner

A provider may disclose a limited subset of information.

Types of information that may be disclosed:

- ▶ diagnosis
- ▶ admission to or discharge from treatment
- ▶ name and dosage of medications prescribed
- ▶ side effects of the medication
- ▶ consequences of the failure of the person with a mental illness to take prescribed medications
- ▶ summary of discharge plan

When a Provider Can Disclose Health Care Information

A provider may release the limited information outlined above about a person with a mental illness to a caregiver when all of the following conditions are met:

- ▶ The request for information is in writing.
- ▶ The person with a mental illness is informed in writing of the request, the name of the caregiver requesting the information, the caregiver's reason for the request, and the specific information being requested.
- ▶ The person with a mental illness agrees to the disclosure, does not object to disclosure, or is unable to consent or object because of his or her condition.
- ▶ The disclosure is necessary to assist in the care or monitoring of the person's treatment.

The provider may give the caregiver the information in writing or verbally. If the caregiver has a pre-existing relationship with the provider, it is more likely that the information will be given verbally, for example, over the phone.

When a Provider Cannot Disclose Health Care Information

There are two situations where the provider cannot provide the limited information to a caregiver about a person's mental health. These occur if a provider reasonably believes that:

- ▶ giving the information would be harmful to the physical or mental health of the person with a mental illness, OR
- ▶ giving the information is likely to cause the person with a mental illness to inflict self harm or to harm another.

Preparing for Disclosure of Health Care Information

Caregivers need to establish proof that they are a caretaker of the person with a mental illness by:

- ▶ keeping a document on hand showing you have the same address as the person with a mental illness
- ▶ having a signed note from a physician or mental health professional that states you are involved in the health care of the person with a mental illness and making sure this is in his or her medical records
- ▶ maintaining a folder of medical records that show you are a caregiver of the person with a mental illness

Caregivers can also maintain a file containing all or some of these things that can be shown to the provider that you are a caregiver of the person with a mental illness. It is also helpful to write out the list of information needed to assist in providing care to the person with a mental illness. Caregivers can fill out a form in advance to ensure they have requested everything needed from the provider to assist in the health care of the person with a mental illness. ■

HIPAA PRIVACY RULE

According to the U.S. Department of Health and Human Services, the HIPAA Privacy Rule at 45 CFR 164.510(b) recognizes “the integral role that family and friends play in a patient’s health care to allow these routine—and often critical—communications between health care providers and these persons. Where a patient is present and has the capacity

to make health care decisions, health care providers may communicate with a patient's family members, friends, or other persons the patient has involved in his or her health care or payment for care, so long as the patient does not object. The provider may ask the patient's permission to share relevant information with family members or others, may tell the patient he or she plans to discuss the information and give them an opportunity to agree or object, or may infer from the circumstances, using professional judgment, that the patient does not object" (e.g., a patient invites a family member into the treatment room).

When a person is not present or is incapacitated, "a health care provider may share the patient's information with family, friends or others involved in the patient's care or payment for care, as long as the health care provider determines, based on professional judgment, that doing so is in the best interests of the patient. Note that, when someone other than a friend or family member is involved, the health care provider must be reasonably sure that the patient asked the person to be involved in his or her care or payment for care."

This permission clearly applies where a patient is unconscious. However, there may be additional situations in which a health care provider believes, based on professional judgment, that the patient does not have the capacity to agree or object to the sharing of personal health information at a particular time and that sharing the information is in the best interests of the patient at that time. These may include circumstances in which a patient is suffering from temporary psychosis or is under the influence of drugs or alcohol. If, for example, the provider believes the patient cannot meaningfully agree or object to the sharing of the patient's information with family, friends, or other persons involved in their care due to their current mental state, the provider is allowed to discuss the patient's condition or treatment with a family member, if the provider believes it would be in the patient's best interests. In making this determination about the patient's best interests, the provider should take into account the patient's prior expressed preferences regarding disclosures of their information, if any, as well as the circumstances of the current situation. Once the patient regains the capacity to make these choices for herself, the provider should offer the patient the opportunity to agree or object to any future sharing of their information.

Hospitals may notify family, friends, or caregivers of a patient who has been hospitalized for a psychiatric hold has been admitted or discharged in several circumstances:

When the Patient has a Personal Representative

A hospital may notify a patient's personal representative about their admission or discharge and share other PHI with the personal representative without limitation. However, a hospital is permitted to refuse to treat a person as a personal representative if there are safety concerns associated with providing the information to the person, or if a health care professional determines that disclosure is not in the patient's best interest.

When the Patient Agrees or Does Not Object to Family Involvement

A hospital may notify a patient's family, friends, or caregivers if the patient agrees, or doesn't object, or if a health care professional is able to infer from the surrounding circumstances, using professional judgment that the patient does not object. This includes when a patient's family, friends, or caregivers have been involved in the patient's health care in the past, and the individual did not object.

When the Patient becomes Unable to Agree or Object and There has already been Family Involvement

When a patient is not present or cannot agree or object because of some incapacity or emergency, a health care provider may share relevant information about the patient with family, friends, or others involved in the patient's care or payment for care if the health care provider determines, based on professional judgment, that doing so is in the best interest of the patient. For example, a psychiatric hospital may determine that it is in the best interests of an incapacitated patient to initially notify a member of their household, such as a parent, roommate, sibling, partner, or spouse, and inform them about the patient's location and general condition. This may include, for example, notifying a patient's spouse that the patient has been admitted to the hospital. If the health care provider determines that it is in the patient's interest, the provider may share additional information that is directly related to the family member's or friend's involvement with the patient's care or payment for care, after they clarify the person's level of involvement. For example, a nurse treating a patient may determine that it is in the patient's best interest to discuss with the patient's adult child, who is the patient's primary caregiver, the medications found in a patient's backpack and ask about any other medications the patient may have at home. Decision-making incapacity may be temporary or

long-term. Upon a patient's regaining decision-making capacity, health providers should offer the patient the opportunity to agree or object to sharing their health information with involved family, friends, or caregivers.

When notification is needed to lessen a serious and imminent threat of harm to the health or safety of the patient or others

A hospital may disclose the necessary protected health information to anyone who is in a position to prevent or lessen the threatened harm, including family, friends, and caregivers, without a patient's agreement. HIPAA expressly defers to the professional judgment of health professionals in making determinations about the nature and severity of the threat to health or safety. For example, a health care provider may determine that a patient experiencing a mental health crisis has ingested an unidentified substance and that the provider needs to contact the patient's roommate to help identify the substance and provide the proper treatment, or the patient may have made a credible threat to harm a family member, who needs to be notified so he or she can take steps to avoid harm. OCR would not second guess a health care professional's judgment in determining that a patient presents a serious and imminent threat to their own, or others', health or safety.

Access to data is not unlimited. The Privacy Rule ensures that "in all cases, disclosures to family members, friends, or other persons involved in the patient's care or payment for care are to be limited to only the protected health information directly relevant to the person's involvement in the patient's care or payment for care."

If a person has capacity and objects to the provider sharing information, the law says that "the provider may only share information if doing so is consistent with applicable law and standards of ethical conduct, and the provider has a good faith belief that the patient poses a threat to the health or safety of the patient or others, and the family member is reasonably able to prevent or lessen that threat.* Otherwise, under HIPAA, the provider must respect the wishes of the adult patient who objects to the disclosure."

Otherwise, if the patient has capacity and objects to the provider sharing information with the patient's family member, the provider may only share the information if doing so is consistent with applicable law and standards of ethical conduct, and the provider has a good faith belief that the patient poses a threat to the health or safety of the patient or others, and the family member is reasonably able to prevent or lessen that threat. See 45 CFR 164.512(j). For example, if a doctor knows from experience that, when a patient's medication is not at a therapeutic

level, the patient is at high risk of committing suicide, the doctor may believe in good faith that disclosure is necessary to prevent or lessen the threat of harm to the health or safety of the patient who has stopped taking the prescribed medication, and may share information with the patient's family or other caregivers who can avert the threat. However, absent a good faith belief that the disclosure is necessary to prevent a serious and imminent threat to the health or safety of the patient or others, the doctor must respect the wishes of the patient with respect to the disclosure.

The Privacy Rule permits a health care provider to disclose necessary information about a patient to law enforcement, family members of the patient, or other persons, when the provider believes the patient presents a serious and imminent threat to self or others.

HIPAA does not prohibit health care providers from listening to the confidential concerns of family or caregivers about the health and well-being of a person with a mental illness. Under CFR 164.524(a)(2)(v), "in the event that the patient later requests access to the health record, any information disclosed to the provider by another person who is not a health care provider that was given under promise of confidentiality may be withheld from the patient if the disclosure would be reasonably likely to reveal the source of the information. This exception to the patient's right of access to protected health information gives family members the ability to disclose relevant safety information with health care providers without fear of disrupting the family's relationship with the patient." ■

*See 45 CFR 164.512(j)

ADDITIONAL SOURCES OF INFORMATION

For more information, contact NAMI Minnesota at 1-888-NAMI HELPS or visit our website at www.namihelps.org. NAMI Minnesota has developed a model form.

**You can also contact the Data Practices Office
of the Minnesota Department of Administration at:**

320 Centennial Office Building

658 Cedar St.

St. Paul, MN 55155

Phone: 651-296-6733 or 800-657-3721

email: info.dpo@state.mn.us

[www.https://mn.gov/admin/data-practices/about/contact-us/](https://mn.gov/admin/data-practices/about/contact-us/)

**You can also contact the Office for Civil Rights–HIPAA,
at the U.S. Department of Health and Human Services at:**

www.hhs.gov/ocr/hipaa/ ■

SAMPLE FORMS

Example of Caregiver Request Form for Mental Health Care Information About a Person with a Mental Illness

I, _____ am requesting the
NAME OF PERSON MAKING THE REQUEST FOR INFORMATION
following information from the health care records of

NAME OF PERSON

Information about diagnosis
Admission to treatment
Discharge from treatment
Summary of discharge plan
Name and dosage of the medication prescribed
Side effects of the medication, and
Consequences of failure to take the prescribed medication

I am not asking you to release the person's entire health record.
I am directly involved in the mental health care of this person.

This information is necessary for me to assist in the care of the person
named above or monitoring his or her treatment because

I understand that you, as the provider, may give me the information I
request if the person named above agrees to my request, does not object
to my request, or is unable to consent or object to my request. You can
give this information to me verbally or in writing.

My contact information is:

Telephone: (Day) _____

(Evening) _____

Address: _____

I certify that I live with, provide care for, or am directly involved in monitoring

This information can be verified by _____

Signature _____

Date signed _____

I certify that I currently provide mental or health care to

NAME OF PERSON

NAME OF CAREGIVER REQUESTING INFORMATION

lives with, provides care for or is directly involved in monitoring the treatment of _____

SIGNATURE _____

DATE SIGNED _____

Form for Permission to Release Private Information from Health Records by (Name of Provider that Maintains the Information)

[NAME OF PROVIDER THAT MAINTAINS THE INFORMATION] is asking for your consent (permission) to let us release information about your diagnosis, admission or discharge from treatment, name and dosage of medication(s) prescribed, side effects of the medication(s), consequences of your failure to take prescribed medications, and summary of discharge plan from your health care records to [NAME OF FAMILY MEMBER OR CARETAKER REQUESTING THE INFORMATION]. *This is not a release of information to release all of your health care records.* This consent only covers the information listed above. You have the right to give us permission to release all of the information, some of the information or none of the information described on this form: Please check the items that you grant permission to be released to [NAME OF FAMILY MEMBER OR CARETAKER].

- diagnosis
- admission or discharge from treatment
- name and dosage of medication(s) prescribed
- side effects of the medication(s)
- consequences of your failure to take prescribed medications
- summary of discharge plan from your health care records

If you give us your consent, we can release the information [FOR SPECIFIED TIME PERIOD OR UNTIL EVENT OR CONDITION]; however, we can still release the information if you do not sign this form and fail to object to disclosure or are unable to consent or object. You have the right to stop your consent (revoke or take back your permission) any time before [THIS TIME PERIOD, EVENT, OR CONDITION]. If you want to stop your consent, you must write to [IDENTITY OF AND CONTACT INFORMATION FOR THE APPROPRIATE EMPLOYEE OF THE PROVIDER] and clearly say that you want to stop or take back all or part of your consent.

Important: If you have a question about anything on this form, please talk to [NAME OF APPROPRIATE PROVIDER EMPLOYEE AND HOW TO CONTACT THAT PERSON] before you sign it.

[A] I, _____, give my permission for [PROVIDER] to release information from my health records about diagnosis, admission to treatment, discharge from treatment, summary of discharge plan, name and dosage of medications, side effects of medications, and/or consequences of failure to take prescribed medications;

[B] I agree to let [PROVIDER] release this information to [FAMILY MEMBER OR CARETAKER];

[C] I understand that [PROVIDER] needs to release the information in these way(s) in order to assist [FAMILY MEMBER OR CARETAKER] in the care or monitoring of the my treatment;

[D] I understand that, if this information is released to these individuals, the results will be [].

[E] Signature of patient _____

Date signed _____

[F] Signature of parent or guardian _____

Date signed _____

[G] Signature of person explaining this form and the patient's rights

Date signed _____

Instructions for the Provider that Maintains the Health Records

- ▶ To adapt this model form to your specific needs, insert the appropriate language where indicated by the bracketed text on the form.
- ▶ Lettered instructions below correspond to the bracketed letters on the consent form.
- ▶ Use language and syntax that are clear, easy to understand and appropriate for the person with a mental illness.

Have the person with a mental illness print their name in the space provided. Enter the complete name and address of your entity as the provider. Include relevant program names, staff names, titles and phone numbers.

Describe *the caretaker who has asked to have information released*. Include phone numbers and addresses. *Be clear and specific*.

Describe specifically and completely why your entity needs to release the information to the individual(s) identified on the form.

Describe specifically and completely the consequences of releasing the information to the individual(s) identified on the form. Include all of the consequences that are known to the provider at the time the consent is signed if the consequences of the release differ according to the person's choices on the form; describe these differences clearly and completely.

Direct the person with a mental illness to sign the consent and enter the date of signature.

As a general rule, it is advisable to obtain a parent or guardian's signature when the client is under the age of 18 or has a legally appointed guardian; however, the specific requirements for obtaining consent to release information in these circumstances vary. For this reason, instructions for completing this portion of the form within your entity should be developed in consultation with your legal advisor.

Any person who discusses the request for consent with the person with a mental illness should sign the consent and enter the date of signature.

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MINNESOTA

1919 University Ave. W, Suite 400

St. Paul, MN 55104

Phone: 651-645-2948

Toll Free: 1-888-626-4435

Fax: 651-645-7379

E-mail: namihelps@namimn.org

Web: www.namimn.org

