

Sharing That Builds Trust and Honors Privacy

Chapter 2

At a Glance

What's this chapter about?

This chapter looks at:

- Building trust
- Concerns about information sharing
- Privacy laws
- How to get consent
- Sharing information without consent

What's the most important thing to know about information sharing?

Trust. It's the key to supporting good communication between the family and the rest of a child's network.

What are the main concerns with information sharing?

Five of the most common concerns are:

- Understanding laws and regulations
- How much information to share
- Getting and sharing the information needed
- Sharing incorrect information
- Sharing other family members' information

What are the main privacy laws?

The main privacy laws are:

- HIPAA (Health Insurance Portability and Accountability Act)
- FERPA (Family Educational Rights and Privacy Act)
- Title 42 of the Code of Federal Regulations, Part 2
- Massachusetts General Laws Chapter 112

Building Trust

Building trusting relationships between the family and the rest of the child’s network supports good communication. To build trust:

- Make sure the right information gets to the right people — and not to anyone else.
- Work with family and youth to set rules for information sharing.
- Let the family know that to protect the child’s health and safety, some information can be shared without consent.
- Make sure the family understands what information they agree to share. This is called informed consent.
- Follow the rules set by family and youth.
- Smile, shake hands, and look people in the eye, when culturally appropriate.

Privacy laws for health care providers and schools do allow some information to be shared without consent. If information will be shared without consent, then it’s very important to let the family know what will be shared and with whom.



To learn more about the importance of getting consent, you can read [Consumer Control of Mental Health Information](#) on the Mental Health Legal Advisors Committee website.

Common Concerns about Information Sharing

Every team in a child’s network has concerns about sharing information, from confusion about privacy laws to sharing too much — or too little — information. Five of the most common concerns are:

- Understanding laws and regulations
- How much information to share
- Getting and sharing the information needed
- Sharing incorrect information
- Sharing other family members’ information

Understanding Laws and Regulations

Privacy laws and regulations are confusing. It's not always clear what information can be shared, who can look at the information, and if consent is needed.



Read this Guide to help you understand privacy law basics and when to get consent.



How Much Information to Share

Caregivers have to find the right balance when sharing information. A caregiver who doesn't have enough information may give the wrong care, or even no care at all. For example, in Tommy's case (see page 11 for Tommy's story), if the school nurse doesn't know his medication has changed, she may give him the old medication. This affects Tommy's health and safety.

Good communication depends on trusting relationships. If caregivers share too much information, or if they share information with someone who doesn't need to know it, they can damage the relationship with the child and family. For example, if the behavioral health provider tells the school nurse about a medication that Tommy's mother takes, or if the school nurse tells another student about Tommy's new medication, then Tommy and his family may be less likely to share important information with their caregivers in the future. When trust is broken, communication suffers, and it gets harder for everyone to give Tommy the care he needs.



Share only enough information to make sure the child gets the care needed and stays safe.



Getting and Sharing the Information Needed

People who work together regularly know their own teams well. They know the information they need, where they can go for more details, and who can answer questions for them. But when working outside their teams, it can get complicated.

For example, when a family starts working with a behavioral health provider, they

may not even know the questions to ask or the important information to share. A primary care provider working with a new school has the same challenges.

This is why it's helpful to share the reasons that information is being asked for or given. When people know why information is being shared, they don't have to guess at what might be important — they'll know, and they'll share the right information.



When asking for information, tell the other person what you need and why you're asking.



When giving information, tell the other person why you're giving it to them and why it's important.



Sharing Incorrect Information

When incorrect information gets shared, providers and schools may give care that harms a child or family, or may not deliver care at all. In Tommy's case, if the school nurse gets the wrong dosing information for his new medicine, then he'll get too much or too little medication.



Always double check the information you're sharing. Make sure it fits with what you know, and that it's the right child's information. Whenever possible, ask the family to check the information — families play an important role in finding incorrect information.



Sharing Other Family Members' Information

Families need to know that only the right information is getting shared. A child's records may include details about other family members, and those details can't be shared unless they relate to the child's health and safety. For example, when giving care to an infant, it would be important to note signs of depression in the mother.



Review a child's records before releasing them. Make sure they contain only the information needed to treat the child. Ask the family or youth to check the information for you.



What Are the Main Privacy Laws?

The main privacy laws are:

- HIPAA (Health Insurance Portability and Accountability Act)
- FERPA (Family Educational Rights and Privacy Act)
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Please note that this Guide provides general information about privacy laws and ethical standards, but it doesn't provide legal advice. The Guide is not meant to replace an organization's policies and procedures.

For links to the full laws, as well as other laws and regulations, see page 95.

HIPAA

HIPAA is a federal law that protects the privacy of protected health information (PHI). PHI includes medical records and information used by health plans, doctors, hospitals, and other health care providers. HIPAA gives patients a number of rights about their PHI.

HIPAA gives patients the right to:

- Read and make copies of PHI
- Change PHI
- Ask to limit how PHI can be used
- Not allow PHI to be sold, used for marketing reasons, or used for research
- Ask for a list that shows who's allowed to look at PHI
- Complain about a HIPAA privacy violation

FERPA

FERPA is a federal law that protects the privacy of public school student education records. The FERPA law does not apply to private schools. FERPA gives parents or guardians rights about their children's education records. These rights become the student's rights when the student:

- Turns age 18
- Starts school beyond the high school level, like college, even if the student is under age 18

A student who has FERPA rights is called an **eligible student**.

Generally, schools can't release any information from a student's education record without written consent from the parent or eligible student. However, because school nurses are providers under HIPAA, they can share information with other providers without consent.

FERPA gives parents and eligible students the right to:

- Look at all the student's education records kept by the school
- Ask that the school correct records if something isn't right

Health Information in Education Records: HIPAA or FERPA?

Health information contained in a medical record is protected by HIPAA. Health information given to anyone in the school goes into the student's education record. Once it's in the education record, it's protected by FERPA, not HIPAA. That doesn't mean that anyone working in the school can see the health information record. For example, information given to the school nurse is kept in a secure part of the school's record. It's only shared on a need-to-know basis.

Title 42 Code of Federal Regulations, Part 2

Title 42 is a federal regulation that protects alcohol and drug abuse treatment records. It says that most of the time, federally-funded drug and alcohol abuse programs can't share patient information without the patient's consent.

In many states, including Massachusetts, Title 42 gives special protections to minors. If state law lets minors sign up for drug and alcohol abuse programs without telling their parents – and Massachusetts does – then Title 42 says that only the minor can give written consent for sharing their treatment records. In most cases, this means that even the parents need the minor's written consent to view the records.

Massachusetts General Laws Chapter 112

Chapter 112 of the Massachusetts General Laws has rules for certain professionals, such as therapists, about licenses, treatment, and sharing patient information.

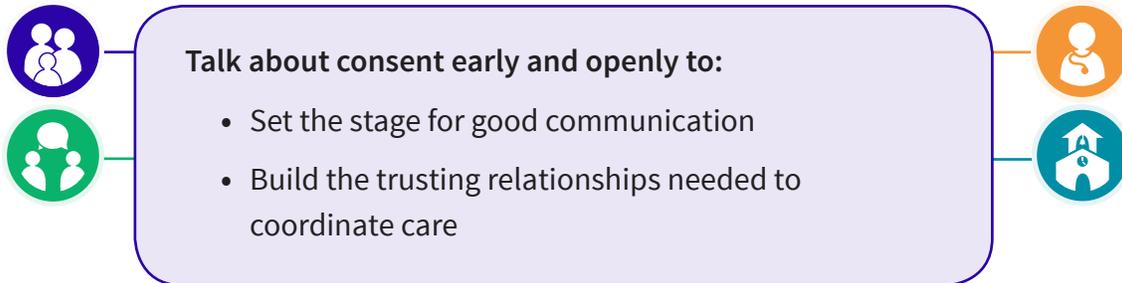
Section 172 of the law protects the privacy of any communication between an allied mental health or human services professional and a patient. Information between a mental health professional and a patient can only be shared when the patient agrees to have the information shared, or when:

- The mental health professional is a defendant in a case about the services they provided
- The patient is a defendant in a criminal case, and keeping the information private would take away the patient's right to get witnesses and give testimony
- The information shows that the patient thought about — or committed — a crime or harmful act

Section 12CC of the law protects patients' rights to see their records — a health care provider has to let the patient or an authorized representative look at their records. If a behavioral health provider thinks that releasing the entire record could harm the patient or others, they may provide a summary of the record to the youth or family.

How to Get Consent

Children might have information in a number of records, such as health records, education records, and treatment records for substance abuse. There are different rules for each of these records about whether consent is required and how to store and share the information. Providers and schools need to come together, create treatment team consent forms, and work with families and youth around the kinds of consent needed.²



Youth and their parents have the final say in what to share and who to share it with. This is a key to building trust and creating relationships that support information sharing. In order to be meaningful, youth or families need to give informed consent.

Informed consent means that the youth or family clearly understands:

- What will be shared
- Who it will be shared with
- The risks and benefits of sharing

Once the family or youth has agreed to share information, their consent needs to be put in writing. A written consent is also called a **release of information**. Written consent needs to be:

- Signed and dated by the family or youth.
- Given an end date. Consent can only be given for a set time. The end date chosen needs to meet the privacy needs of the family or youth and the needs of the person asking for information.

Families can change their minds about consent. They can change what information they want shared, change the end date, or totally end their consent at any time.

For sample consent forms, see pages 119 to 128.

Who to Ask for Consent

Every family is different, which can make it challenging to know who to talk to about consent for treatment and information sharing. Keep in mind that:

- The legal guardian for the child is the decision maker. To find out who the guardian is, start by asking the family. To learn more about guardians, see page 35.
- Youth may be able to make decisions about care and communication without their parents or guardian. Even if the youth is not the decision maker, it's usually best to include youth in discussions since decisions are being made about their care.

As children become adolescents, they communicate more for themselves with providers and schools. They need to take part in making decisions about information sharing. When seeking consent for:

- Children, ask the parents or guardians about what information to share and who to share it with
- Youth, include the youth in the discussion about what information to share and who to share it with

When a youth turns age 18, the youth makes the decisions about sharing and consent, unless an adult has guardianship. Youth ages 18 and older can give consent for parents or anyone else to see their records, if they wish.

Consent and the Rights of Minors

There are times when a youth under age 18 (a minor) makes decisions about sharing and consent. Minors have the right to give consent without permission from their parents if:

- They are legally independent from parents
- A doctor uses the mature minor rule
- Other consent rules apply

Minor Is Legally Independent

Emancipation is when a minor becomes legally independent from his parents and can make his own decisions. In Massachusetts, there is no formal legal process for emancipation, but a minor can file a “Complaint in Equity” in the Probate and Family Court. A Complaint in Equity asks to end the parents’:

- Responsibility for the child’s support
- Right to make decisions for the child, including providing consent

Mature Minor Rule

A provider has to get consent from parents for regular doctor visits and medical care given to a minor, unless it’s an emergency. The Massachusetts “mature minor rule”³ lets a doctor give certain care with only the child’s consent if the doctor believes that:

- The child is mature enough and able to give informed consent to medical care
- It’s in the best interests of the child to **not** ask the parents

Other Consent Rules

Based on other consent rules:

- Minors may consent to their own treatment for drug addiction, family planning services, or treatment for sexually transmitted diseases, including HIV or AIDS⁴
- Minors age 16 and older may get mental health treatment without consent from parents⁵



For more information about the rights of minors, visit the [Children’s Law Center of Massachusetts](#) website.



Tips on Sharing Information

When sharing information that requires consent, keep in mind to:

- Share only the information the youth or family have agreed to
- Share only with the people the youth or family have agreed to
- Secure the information shared so that only the right people have access to it



What Can Be Shared Without Consent?

Different laws protect different kinds of information. These laws also define when consent is needed:

- HIPAA has rules about sharing health care records without consent
- FERPA has rules about sharing education records without consent

When can health records be shared without consent under HIPAA?⁶

- When sharing information with another provider to help treat the patient (There are exceptions for behavioral health. For example, psychotherapy notes can't be shared.⁷)
- In a health and safety emergency
- For research and improving quality, as long as the patient's identity is not given
- For managing billing and claims

When can education records be shared without consent under FERPA?^{8,9}

- When school officials need to look at them for educational reasons
- When another school needs them because the student is changing schools
- For audits and evaluations
- When an organization needs to check that the school is meeting rules and standards
- When a judge's order or subpoena requires sharing
- In a health and safety emergency