communication matters

A guide for sharing information about a child’s care

Developed by the Massachusetts Child Health Quality Coalition, June 2014
How to Use this Guide

The Guide provides information to support communication among 4 teams:

- Children, youth, and families
- Primary care providers
- Behavioral health providers
- Schools

Chapters 1-3 have information that’s useful to all teams. Each chapter builds on the one before it, so it’s helpful to read them in order.

Chapters 4-7 each provide specific information for one team. For example, chapter 7 is written for the school team. These chapters are meant to stand alone for easy reference by team members.

Throughout the Guide, icons identify content meant for a specific team:

- Children, Youth, and Families
- Primary Care Providers
- Behavioral Health Providers
- Schools
- Web Link
- Quote

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For more information about the MA Child Health Quality Coalition, visit www.mhqp.org.
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About This Guide

In 2010, the Centers for Medicare and Medicaid Services gave Massachusetts a CHIPRA (Children’s Health Insurance Program Reauthorization Act) Quality Demonstration Grant.

With the grant, Massachusetts created the Child Health Quality Coalition (CHQC) to:

- Work to improve child health care quality and ways to measure the quality of that care
- Find important gaps in child health care quality across the state and find ways to address those gaps

CHCQ members include:

- Doctors, hospitals, and health professional groups
- Parents and family advocates
- Health insurance plans
- State and local agencies
- Community groups
- Policy experts

What Are Important Gaps in Child Health Care Quality?

The CHQC reviewed data on child health care quality in Massachusetts and found that some of the major gaps were in:

- Coordinating care for all children, with a special focus on children with behavioral health needs
- Understanding how communication and privacy challenges can limit sharing information that is needed to coordinate care

To address the communication and privacy issues, the CHQC formed a Communication and Confidentiality Task Force. This task force included families, providers, school staff, lawyers, and advocacy groups.
Why Write the Guide?

The Task Force found that some families, schools, and providers have already found ways to share information so that children and their families receive coordinated care that respects privacy concerns. But how they built these networks isn’t common knowledge. Many families, schools, and providers simply don’t know about the helpful tools and systems they could be using.

The Task Force created this Guide to:

- Share information on rules and laws
- Collect communication support tools and systems in one place
- Share the experience of families, schools, and providers to show the clear need for sharing information in a way that respects privacy
- Give information on building and maintaining trusting relationships

Who’s the Guide for?

The Guide focuses on communication between the:

- Child, youth, and family
- Primary care provider
- Behavioral health provider
- School team

Even though the Guide focuses on these four groups, the tips and information presented here are just as useful to other members of a child’s network, including:

- Specialists other than behavioral health care providers
- Community-based programs (such as Early Intervention)
- Peer supports

This Guide can also be helpful for addressing communication and privacy issues when caring for adults.
Why Share Information?

At a Glance

What’s this chapter about?
This chapter looks at:
• How good communication helps support better child health care
• Ways to support good communication
• Respecting differences in language and culture

Why is information sharing important?
Good information sharing leads to better care because it:
• Creates stronger networks
• Gives a clearer picture of a child’s health
• Builds a base of trust and respect for privacy
• Leads to better use of everyone’s time and resources

What are the basics of good communication?
To support good communication for a child’s care:
• Put the family first
• Build trusting relationships
• Protect privacy

How do language and culture come into play?
Even between two people speaking the same language, the same word can mean two very different things. With different cultures, a little more work is needed to put everyone at ease. Then, they can focus on the same goal — giving care to the child.
Introduction

The goal of this Guide is to improve child health care through better communication between the:

- Child, youth, and family
- Primary care provider
- Behavioral health provider
- School team

The Guide gives:

- Tips for building and maintaining trusting relationships
- Tools and ideas for sharing information
- A system to identify everyone who takes part in caring for a child
- An overview of privacy laws and how to use them

The terms child and parent are used throughout the Guide. Every family is different, but to keep the Guide focused, these terms are used in the following way:

- **Child** means a person ages 0 to 21
- **Parent** means a parent, guardian, or anyone else with the legal right to make decisions for and with a child
- When referring to issues for older children, we may use the term youth

Better Communication Means Better Care

Good communication means sharing the right information with the right people at the right time, while always respecting privacy. It takes trust, work, and strong relationships.

But why is information sharing so important to a child’s health? And how can everyone who takes part in a child’s care support better communication?
A Small Change Leads to Big Questions: Tommy’s Story

Meet Tommy, age 9. Tommy has many medical and behavioral health care needs:

- He sees his primary care provider (PCP), a behavioral health provider, and other doctors.
- He sees the school psychologist as part of his Individualized Educational Plan (IEP).
- He takes many medications, some prescribed by his PCP and some by his behavioral health provider.
- The school nurse gives him his medications during the school day.

Tommy’s family sees that his behavior is not improving, and wonders if his medications are not helping him. They call Tommy’s behavioral health care provider, who makes a change in medications. People involved with Tommy need to know about this change because:

- The school nurse has to give Tommy the new medication, not the old one. The nurse also has to keep an eye on the effects of the new medication.
- The family can help the school psychologist know how Tommy is doing with the new medication.
- The PCP has to check on how the new medication works with Tommy’s other medications.

One small change has a big effect on Tommy and the people who care for him. It also leads to a lot of questions, such as:

- How will everyone get the information they need?
- Will Tommy’s behavioral health care provider tell anyone about the change?
- Can the behavioral health provider share information without asking Tommy’s family?
- Will the school psychologist talk to Tommy’s family to let them know how he is doing?
- Will the school nurse know that she needs to give Tommy a new medication?
- How is the information kept private, so that only the people who need it can see it?
Information Sharing Creates Stronger Networks

All the people involved with a child make up the child’s network. This includes families, schools, medical and behavioral health providers, and community groups, each with a different and important role in keeping the child well.

Tommy’s story shows how one small change can touch so many people in the network. How can we be sure that Tommy gets the care he needs? All the people in the network need to give and receive information about Tommy. That happens when there is a strong, trusting network among all the people involved with Tommy, and systems are in place to support communication, so that he can get the care he needs.

Every person in a child’s network has something to offer, and when they share, the child’s care only gets better:

- Parents are the experts on their child. They need to be heard and supported in sharing what they know.
- Each person sees the child through a different lens. It’s only possible to see the whole picture of a child’s health when everyone shares information.
- Good communication means better use of time and resources.
- When the network is strong, everyone knows who to communicate with and how to reach the people they need.
- Clear communication helps the right information get to only the right people.

Supporting Good Communication

Good communication makes a child’s network stronger, but it can be challenging sometimes. To build and maintain a good flow of communication, so that everyone has the information they need to keep the child safe and healthy, start with the basics:

- Put the family first
- Build trusting relationships
- Protect privacy

Put the Family First

Family-driven care and youth-driven care are keys to building trust and good communication in the child’s network. In this type of care, families and youth, providers, and other members of the child’s network all take part in making decisions, and they all share responsibility for the results.
Families and youth become partners in their care:

- In family-driven care, families and providers work together to make decisions and set goals about the child’s care together.
- In youth-driven care, families and providers work together to support the youth to make decisions and set their own goals.

For family-driven and youth-driven care to work, schools and providers need to give families and youth information they can understand and act on. This helps them set goals and make better decisions about the services and supports they need.

### The Basics of Family-driven and Youth-driven Care:

- Families, youth, and providers all take part in making decisions, and they all share responsibility for results
- Families and youth get the information they need to set goals and make better decisions about their services and supports
- Providers change their practices from provider-driven to family-driven

To learn more about family- and youth-driven care, you can read the [Working Definition of Family-Driven Care](#) on the National Federation of Families For Children’s Mental Health website.

### Build Trusting Relationships

Good communication and trusting relationships go hand in hand. Trust is:

- Keeping promises
- Treating others with respect
- Communicating honestly

The members of a child’s network build trusting relationships when they:

- Remember that the child, youth, and family are the center of the child’s network
- Build trust early with good communication and respect for privacy
- Set clear, shared goals about what information to share and who to share it with
• Respect the culture and opinions of others
• Check that the information shared is correct

Protect Privacy
Keeping personal information private is one of the keys to good communication and trusting relationships. When sharing information:
  • Give only the information the person needs to care for the child
  • Keep personal information private by using secure systems, tools, and policies
  • Share information using secure systems, so that only the right people can get it

Language and Culture Challenges
Communication can be even more challenging when people have different languages and cultures. Even for two people who speak the same language, the same word can mean two very different things. With different cultures, a little more work is needed to put everyone at ease. Then, they can focus on the same goal — giving care to the child.

When communicating with a child or family, it's important to:
  • Use plain language, not technical terms.
  • Ask questions to make sure everyone understands what is being talked about.
  • Ask them to put what you are saying in their own words. This is called teach back.

To learn more about teach back, try using this tool at the North Carolina Program for Health Literacy website.
Health Care Interpreters

Health care interpreters help providers and families communicate when they speak different languages. They can make sure that the information shared is correct and kept private. If you are working with a professional health care interpreter, ask if they follow the National Standards of Practice for Interpreters in Health Care. These standards require that interpreters keep information private and respect personal boundaries.

For more information about interpreter standards, you can read the National Standards of Practice for Interpreters in Health Care on the Health Resources and Services Administration website.

Working with Different Cultures

People from different cultures may use different words to mean the same thing, or they might not be comfortable talking about certain topics. Learning to work with different cultures leads to better communication and care.

“Individuals can embody multiple cultures and differences often exist between people from the same group and it’s essential to acknowledge that each person is unique and may reveal his or her culture in their own distinct way.

When programs strive to be culturally competent, the result should be that families are culturally comfortable. Building an approach that is culturally comfortable starts with communication and awareness. Find out what the family values, who its members are, what the concerns and goals for its children may be. Ask families what matters to them. Find out what is private in a family and what is easily shared. Model respect and show that customs, languages, cultures, and physical attributes different from your own are important and to be honored. Catherine Stakeman, Maine NASW, said that ‘becoming culturally comfortable between all cultures is a journey, and there is always room for improvement.’ To make that happen, it must be everyone’s responsibility.”

—Lisa Lambert
When people work to really understand different cultures, families feel more culturally comfortable. But where to start? Ask the family:

- What matters to you?
- What are your family values?
- Who are the members of your family?
- What are your concerns and goals for your children?
- What’s private in your family? What’s easily shared?

To learn more about culture, language, and health literacy, you can:

- Visit the Health Resources and Services Administration website
- Visit the National Institute for Children’s Health Quality (NICHQ) website
- Visit the Substance Abuse and Mental Health Services Administration (SAMHSA) website
- Read Closing the Gap: Cultural Perspective on Family-Driven Care on the National Federation of Families for Children’s Mental Health website
- Read the Health Literacy Fact Sheet at the Center for Health Care Strategies website
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
Sharing That Builds Trust and Honors Privacy

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)
- Title 42 Code of Federal Regulations, Part 2
- Massachusetts General Laws Chapter 112

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” 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 AIDS
• Minors age 16 and older may get mental health treatment without consent from parents

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?**

- 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.)
- 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?**

- 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
A Closer Look at the Child’s Network

Chapter 3

At a Glance

What’s this chapter about?
Trust and communication help create a strong network for a child. This means sharing the right information and respecting privacy. It also means sharing that information with the right people at the right time. This chapter looks at:

• Who needs information about the child
• How all of the pieces — privacy, the right information, the right people — come together to coordinate the best care
• Who’s on the family team, primary care team, behavioral health team, and school team

What’s a care map?
A care map is a picture of the child’s connections and supports. It’s created by the family and shows both the big picture and the small details of the child’s network.

What’s care coordination?
Care coordination is a structured set of activities to support a child receiving the appropriate services and resources necessary to achieve the best results possible.

Whose role is it to coordinate care?
Care coordination is a family-centered, team-based activity. Families, schools, and providers share responsibilities for making connections and sharing information to support children getting quality care.

What’s the best way to learn about a child’s network?
Ask the family. It’s the same for providers and schools — ask the people on the team to tell you about their organization and needs.
Care Maps

Each child’s network is different. Some are big, some are small, and all of them change over time. So what’s the best way to really understand a child’s network? Ask the family to draw a care map.

A care map is a picture of the child’s connections and supports. It’s created by the family and shows both the big picture and the small details of the child’s network. Care maps are powerful tools — they help families share their experience, supports, and challenges. They give others a clear picture of just how hard it can be to coordinate the right care.10

For example, here’s a care map created by a parent.

Care map drawn by Cristin Lind

This one drawing quickly and clearly shows how many connections a single family can have. Families can use their care map to help share their story and to improve how they work with others in the network.
When providers or schools ask families and youth to create a care map, they help them feel more like partners. It tells the family and youth that their views and ideas matter. Below is a care map drawn by a youth. It shows not just the youth’s connections, but how the youth sees her world.

Learn more about the power of care maps at Durga’s Toolbox website.

To create your own care map, see page 149.
Care Coordination

Care coordination is a structured set of activities to support a child receiving the appropriate services and resources necessary to achieve the best results possible.

The MA Child Health Quality Coalition defines the following five key components as necessary to ensure high-performing care coordination processes:

- Assessment: identifying the family’s care coordination needs
- Care planning and communication
- Working through care transitions (like referral to specialists or leaving the hospital)
- Connecting with schools and community resources
- Transitioning to adult care

What Is Care Coordination?

Care coordination is a structured (deliberate) process that organizes patient care activities among the family and all the other care team members to ensure the appropriate delivery of health care services that meet the family’s needs. Care coordination involves making connections, facilitating referrals, and ensuring effective communication that tracks completion of recommended connections and sharing results of the services provided. Care coordination must address medical, behavioral, and the interrelated social, developmental, educational, and financial needs to achieve the best health and wellness results possible.

Sharing the Role of Care Coordination

Care coordination services are provided by many different members of the child’s network. Many primary care practices have a staff member designated as a care coordinator. Hospitals and specialty practices also offer coordination services to support transitions in care from one setting to another. Each small action needs clear goals and assigned roles. For example, when a doctor gives a referral to see a specialist:

- Who checks if the child actually saw the specialist?
- Who sends the results of the visit back to the doctor who made the referral?

If there are no systems in place for care coordination, it often falls to the families to play a central role. They support care coordination by doing things such as:
• Telling their child’s primary care provider or school nurse that the child went to the emergency department
• Connecting with the local Early Intervention Program
• Making sure that the same tests aren’t given more than once by different specialists
• Making sure all the child’s providers have accurate, up-to-date medication lists

As the care maps show, when children have special health care needs, there is a complex web of services to coordinate. This can be a time consuming process. Families have to take time off work and other family members’ needs often get placed on hold. Providers and schools can help by:

• Asking families how comfortable they are coordinating care
• Finding out where families need help
• Finding ways to help families develop new skills to support their child

Introducing families to mentors — others who have already been down the road — can be hugely helpful.

To ease the stress on families and give better care to the child, the job of care coordination has to be shared by the family, primary care provider, behavioral health provider, and school nurse. Good communication among all members of the child’s network makes sure that people understand and are comfortable with their roles.

Families, schools, and providers need to work together to:

• Set goals
• Understand care coordination needs
• Write care plans that fit the family’s needs
• Find answers to problems like transportation and work schedules
Care Coordination and the Child’s Network

As care maps show, a child’s network has a number of people filling different needs, and all of their work needs to be coordinated. The more people understand about how a child’s network fits together, the stronger the network will be.

The rest of this chapter looks more closely at four of the main teams that make up the child’s network:

- Child, youth, and family
- Primary care provider
- Behavioral health provider
- School team

While there are certainly other important teams in the child’s network, such as community groups, health insurance plans, and medical specialists, this Guide focuses on just these four teams.

A Closer Look at the Child, Youth, and Family Team

Children may have biological parents, adoptive parents, foster parents, or other guardians. They may have a big extended family or a very small one. When people use the word “family”, they’re talking about the people who love and support them, and there’s only way to find out what family means — ask the family.
Understanding Guardians and Custody\textsuperscript{14, 15}

One of the first things to understand about the family is who can make decisions for the child. That means understanding custody and types of guardians.

There are two types of custody:

- Someone with \textbf{legal custody} can make important decisions for the child, such as decisions about education and medical treatment
- Someone with \textbf{physical custody} lives with the child

Understanding who a child lives with provides a clearer picture of what the child’s life is like, but when it comes to consent, it’s legal custody that matters. The following people can have legal custody of a child:

- Birth parents
- Adoptive parents
- Legal guardians

**Birth Parents**

Generally, married parents of the child share physical and legal custody. This is true even if the parents are living apart, unless there is a court order that says something different. If the parents are living apart, there may be court orders that say which parent has the right to make decisions for the child. The parents may share custody roles in any number of ways. For example, they may both share legal and physical custody. Or, maybe only one parent has both legal and physical custody.

> “If the parents have never married, whether they live together or not, the mother always has sole legal custody. The only way an unmarried father can get legal or physical custody is to go to court and ask for a court order. This is true even if he is on the birth certificate.”\textsuperscript{16}

—*Patricia A. Levesh, Esq.*
Adoptive Parents

Adoption is legally taking a child into a family and raising the child as part of that family. Adoptive parents have legal and physical custody of the child.

Legal Guardians for Minors

A Massachusetts court can give custody and care of a child under age 18 to a guardian if:

- A parent gives permission
- The court finds the parent is not able to care for the child

A guardian takes on the role of a parent by:

- Giving a stable home to the child
- Making everyday decisions about a child’s health, education, and safety

For more information about guardians, visit the Massachusetts Guardian Association website.

Legal Guardians for Adults

A Massachusetts court can appoint a guardian to make some or all personal decisions for an adult (age 18 and over) if the adult can’t make or communicate decisions about everyday care, health, and safety.

Legal guardians for adults:

- Make personal and medical care decisions to keep the adult safe and healthy
- Must consider the adult’s desires and personal values when making decisions

Custody and Foster Parents

Foster parents may have physical custody of a child, but do not have legal custody unless the court has made them legal guardians.
## Typical Members of the Child, Youth, and Family Team

The table below shows a number of people who might be part of the family team. Remember, the best way to learn about a family is to ask the family.

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Team Member’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth parents, adoptive parents, and legal guardians</td>
<td>Parents and guardians have legal responsibility for a child’s health and well-being.</td>
</tr>
<tr>
<td>Caregivers</td>
<td>A caregiver is someone who may be responsible for the direct care or supervision of a child. Parents can share the right to make medical and educational decisions with the caregiver. The caregiver doesn’t have to become a legal guardian.</td>
</tr>
<tr>
<td>Foster parents</td>
<td>The Department of Children and Families works with foster parents to take in children who were abused, neglected, or living in unsafe homes. Foster parents help the child keep important connections with their family, school, and community. Foster parents are not allowed to share private information about the child with neighbors and friends. They can share information with court investigators, the child’s lawyer, therapists, doctors, and others, to get care for the child.</td>
</tr>
<tr>
<td>Siblings</td>
<td>Sisters and brothers</td>
</tr>
<tr>
<td>Extended family</td>
<td>Aunts, uncles, grandparents, and cousins</td>
</tr>
<tr>
<td>Family partners and family support specialists</td>
<td>Family partners and family support specialists help the family make informed decisions.</td>
</tr>
</tbody>
</table>
| **Peer mentors** | Peer mentors work with young people who may need extra attention or who don’t have a good support system by:  
  - Giving advice and support  
  - Acting as role models  
  - Providing a positive influence |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Special education surrogate parents</strong></td>
<td>Special education surrogate parents make special education decisions for children in the custody of a state agency.</td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td>Friends are natural supports who share an understanding of trust and respect. Friends give support in challenging times, and they help celebrate life’s successes.</td>
</tr>
</tbody>
</table>
A Closer Look at the Primary Care Team

Just like families, each doctor’s practice is different. A primary care practice could be a doctor’s office, a group practice, or part of a health center.

Typical Members of the Primary Care Team

The table below shows a number of people who might be part of the primary care team. Remember, the best way to know who’s on the primary care team is to ask the practice.

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Team Member’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care providers</strong></td>
<td>Primary care providers (PCPs) are the main health care professionals who take care of the child, including well-child care and managing illness. PCPs may be doctors or nurse practitioners.</td>
</tr>
<tr>
<td><strong>Medical assistants</strong></td>
<td>Medical (or practice) assistants have a number of roles, like:</td>
</tr>
<tr>
<td></td>
<td>• Taking patient history</td>
</tr>
<tr>
<td></td>
<td>• Helping doctors with patient exams and treatment</td>
</tr>
<tr>
<td></td>
<td>• Scheduling appointments</td>
</tr>
<tr>
<td><strong>Nurses</strong></td>
<td>Nurses provide patient care. They may:</td>
</tr>
<tr>
<td></td>
<td>• Give general health care</td>
</tr>
<tr>
<td></td>
<td>• Focus on chronic care, such as managing asthma</td>
</tr>
<tr>
<td></td>
<td>• Provide health education</td>
</tr>
<tr>
<td><strong>Physician assistants, nurse practitioners</strong></td>
<td>Physician assistants (PA) and nurse practitioners (NP) practice medicine under a doctor’s direction. They can:</td>
</tr>
<tr>
<td></td>
<td>• Examine patients</td>
</tr>
<tr>
<td></td>
<td>• Diagnose injuries and illnesses</td>
</tr>
<tr>
<td></td>
<td>• Give treatment</td>
</tr>
<tr>
<td>Role</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Social workers</td>
<td>Social workers help people with problems in their everyday lives. They may diagnose and treat mental health, behavioral, and emotional issues.</td>
</tr>
<tr>
<td>Medical secretaries, Administrative coordinators, Receptionists</td>
<td>Medical secretaries, administrative coordinators, and receptionists are the front desk staff at a doctor's office. They support the practice in giving quality care to children and their families.</td>
</tr>
<tr>
<td>Care coordinators</td>
<td>Care coordinators help manage all the communication needed to care for a child and family. In some practices, this may be one person's job. In others, different people might share this role. Care coordinators can be social workers, nurses, or other health workers.</td>
</tr>
</tbody>
</table>
| Family partners and family support specialists | Family partners and family support specialists help families find resources to meet their needs. They are often parents of children with special health care needs, so they bring valuable, “been there” experience to the family.  
A family partner at the primary care practice may have a different role than a family partner with a behavioral health provider. Be sure to ask what the family partner does at the primary care practice. |
| Patient navigators                        | Patient navigators are health care workers trained to work with different cultures. They support children and families in many ways, such as:  
- Giving information to make better health care choices  
- Helping to coordinate care, get medical services, and find helpful resources |
A Closer Look at the Behavioral Health Team

Behavioral health providers treat people with mental health conditions, substance abuse problems, and other behavioral issues. They give services in a number of places, including emergency departments, outpatient clinics and offices, hospitals, and in homes. This section does not cover behavioral health providers in schools, since they are included in the school team section.

Typical Members of the Behavioral Health Team

The table below shows a number of people who might be part of the behavioral health team. Remember, the best way to know who’s on the behavioral health team is to ask the behavioral health provider.

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Team Member’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrists</td>
<td>Psychiatrists are mental health professionals and medical doctors. They can prescribe medication.</td>
</tr>
<tr>
<td>Psychologists</td>
<td>Psychologists are mental health professionals who provide therapy and psychological testing.</td>
</tr>
<tr>
<td>Neuropsychologists</td>
<td>Neuropsychologists are mental health professionals who test and treat behaviors related to how the brain works.</td>
</tr>
<tr>
<td>Marriage and family therapists</td>
<td>Marriage and family therapists help individuals, couples, families, and groups build better relationships.</td>
</tr>
<tr>
<td>Social Workers</td>
<td>Social workers help people with problems in their everyday lives. They may diagnose and treat mental, behavioral, and emotional issues.</td>
</tr>
<tr>
<td><strong>Psychopharmacologists</strong></td>
<td>Psychopharmacologists are psychiatrists who focus on managing medication.</td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>

**Family partners or family support specialists**

Family partners and family support specialists help families find resources to meet their needs. They are often parents of children with behavioral health needs, so they bring valuable, “been there” experience to the family.

A family partner with a behavioral health provider usually has a different role than a family partner at a primary care practice. Be sure to ask what the family partner does for the behavioral health provider.
A Closer Look at the School Team

Massachusetts has more than 400 public school districts, and each one is different. The school team has professionals for:

- School health services
- Behavioral health supports
- Education

Typical Members of the School Team

The table below shows a number of people who might be part of the school team. Remember, the best way to know who’s on the school team is to ask the school.

<table>
<thead>
<tr>
<th>Team Member: School Health Services</th>
<th>Team Member’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>School nurses</strong></td>
<td>School nurses:</td>
</tr>
<tr>
<td></td>
<td>• Give health care services</td>
</tr>
<tr>
<td></td>
<td>• Manage health programs</td>
</tr>
<tr>
<td></td>
<td>• Are the main contacts for sharing student health information</td>
</tr>
<tr>
<td><strong>School doctors</strong></td>
<td>School doctors work closely with school nurses, but they’re typically not at the school every day. School doctors have a number of roles in the school district, from treating students to health education.</td>
</tr>
<tr>
<td><strong>School-based health centers</strong></td>
<td>Some schools have a school-based health center (SBHC). If a school has an SBHC, then it’s important to communicate with them, as well.</td>
</tr>
<tr>
<td>Team Member: Behavioral Health Supports</td>
<td>Team Member’s Role</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------</td>
</tr>
</tbody>
</table>
| **School psychologists**               | School psychologists:  
- Help children succeed socially, behaviorally, emotionally, and with their school work  
- Provide testing for special education services  
- Give counseling to students  
- Help teachers and parents work with children’s mental health issues |
| **School adjustment counselors**       | School adjustment counselors might be therapists, social workers, or guidance counselors. School adjustment counselors take on many roles, like:  
- Individual counseling  
- Risk assessment and crisis counseling  
- Group counseling  
- Counseling in special education programs  
- Counseling in specialty areas, like substance abuse, depression, and eating disorders  
- Working between schools and outside providers, like a psychologist  
- Helping families  
- Helping faculty  
- Clinical support for faculty and staff  
- Developing behavioral health programs for the school, like anti-bullying education |
<p>| <strong>School-based or school-linked behavioral health services</strong> | Schools or families may hire behavioral health providers from outside the school to work with students. |</p>
<table>
<thead>
<tr>
<th>Team Member: Education</th>
<th>Team Member’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Principals</strong></td>
<td>Principals are administrators who work in the school and manage how the school is run.</td>
</tr>
<tr>
<td><strong>Teachers</strong></td>
<td>Teachers are certified professionals who educate students.</td>
</tr>
<tr>
<td><strong>Teaching assistants</strong></td>
<td>Teaching assistants help teachers and students in the classroom. They sometimes work with students as part of an IEP (Individual Education Plan).</td>
</tr>
<tr>
<td><strong>Special education directors</strong></td>
<td>Special education directors are administrators who run special education within a school or school district. In some districts, this person may be called a student service director, and may also run nursing and counseling.</td>
</tr>
<tr>
<td><strong>Special education teachers</strong></td>
<td>Special education teachers teach children with special needs using IEPs.</td>
</tr>
<tr>
<td><strong>Guidance counselors</strong></td>
<td>Guidance counselors give help and advice to students. They may also help with school-wide programs, such as anti-bullying education.</td>
</tr>
<tr>
<td><strong>Outside consultants</strong></td>
<td>Outside consultants may be hired by the school or family to do a behavioral health assessment or to help develop an IEP.</td>
</tr>
<tr>
<td><strong>School coordinators</strong></td>
<td>School coordinators focus on helping students learn. They may be on support teams, and they may also help the school meet special education standards.</td>
</tr>
<tr>
<td><strong>Tutors</strong></td>
<td>A person who helps students with school work.</td>
</tr>
</tbody>
</table>
A Closer Look at the Child’s Network
Who’s this chapter for?
This chapter is for children, youth, and families.

What’s this chapter about?
This chapter gives best practices and ideas for families who want to:
- Build trusting relationships
- Get and share the right information
- Protect their child’s privacy
- Support their child in the transition to adulthood

How can families build trust with providers and schools?
To build trusting relationships with providers and schools, families can:
- Remember that families are the experts on their own needs
- Take small steps
- Add the right people to their teams

How can families support better communication?
To support better communication, families can:
- Tell their child’s story to help others picture who their child really is
- Connect the people in their child’s network with each other
- Prepare for meetings
- Track where information is going

How does consent and information sharing change as children get older?
As children get older, they become more involved in giving consent and sharing information. Asking children to take part in communication decisions at an early age helps them make better communication decisions as they get older.
Tips for Building Trust

Sharing information works best when your child’s network is built on honest and trusting relationships. That takes time, but it makes a big difference in how you work with your child’s school and providers. Three things you can do to get started are:

- Remember that you’re the expert
- Take small steps
- Add the right people to your child’s network

Remember That You’re the Expert

- No one knows more about the needs of your child and family than you do. You build trust in yourself and your relationships when you show that you know more about your child than anyone else, and when you share helpful information about your child that others may not know.
- Take part in creating treatment plans and making decisions. Remember, you have the final say in decisions about your child.
- Help people in your network set expectations and understand each other’s goals. Asking about other people’s needs is a great way to build trust and understanding.
- Say something if you don’t feel safe or comfortable. The people in your child’s network have different experiences and cultures. You need to help others understand your personal boundaries.

Take Small Steps

You can take many small steps to build strong and trusting relationships. For example, you can:

- Join a group of families facing challenges like yours. It’s easier to share information with people you connect and feel comfortable with. You’ll learn how to talk about your needs and to start trusting new people. If there aren’t any groups for you, think about starting one.
- Build a relationship with someone you trust at the school. Talk to them regularly, not just in a crisis. Consider setting up a meeting with the school nurse when your child starts at a new school.
• Meet face-to-face with people in your network. If face-to-face meetings are not possible, then think about using technology such as Skype or Face Time for meetings.

• Start by sharing pieces of information about yourself or your child. You can always tell them more as you gain trust in the relationship.

Add the Right People

When you need to add people to your child’s network, you may want to:

• Talk to them first to see if they’re a good fit.

• Look for people who understand your culture.

• Ask about their experience and license (if they need one). Check to make sure they have the right license or other training they need.

• Find people who go the extra mile to give the best care.

• Ask how long the person will work with you. This sets everyone’s expectations, an important part of building trust.

Getting the Information You Need

Getting the information you need often means asking the right questions. Because every provider and school is different, there’s not just one way to ask for what you need. Use the questions below for ideas about the kinds of things you may want to ask about.

General Questions to Ask Schools and Providers

• What strengths do you see in my child?

• Do you have all the consents you need to get and share the right information about my child?

• How can I track where information about my child goes?

• How can I be sure that the information in my child’s record is correct?

• If I correct something in my child’s record, how can I be sure that it gets updated?
Questions to Ask Schools About Education

- Why are you recommending this education plan? How will it help my child?
- What can I do to help the education plan succeed?
- Do you think that my child’s education plan is working well? Do you see any ways to make it work better?
- How can we work together to make sure that my child is able to learn?

Questions to Ask Schools about Health Services

- Who’s the school nurse?
- What’s the school nurse’s contact information?
- Who else at the school works with my child, and what is their contact information?
- Can I talk to the school nurse about the best way to share information about my child?
- How will information I give the school nurse be stored?
  Note: Any information you give the school nurse should be stored securely, whether it’s on paper or saved on a computer.
- How will the information I give the school nurse be shared? Who else is allowed to look at it?
  Note: Information should only be shared for your child’s education or safety needs.
- How will you make sure that information doesn’t get shared with people at the school who don’t need to know it?
School Re-entry Programs

A student returning to school after a behavioral health or medical issue (such as a concussion) faces special challenges. Creating a school re-entry plan can be helpful to the student and everyone involved in the student’s care. Some schools in Massachusetts have re-entry programs where a coordinator creates a team to help ease the youth back into school.

Coordinators may:

- Provide clinical care
- Give support and information
- Help families negotiate the social service network
- Manage communication with health care providers and therapists
- Work with students, teachers, and tutors

For more information about school re-entry programs, visit:

- The [Metrowest Health Foundation](#) website
- The [Brookline Resilient Youth Team Program](#) website

Questions to Ask Providers

- Why are you suggesting this treatment plan? How will it help my child? Are there other treatment options? What are the risks and benefits?
- What can I do to help the treatment plan succeed?
- Do you think my child’s treatment plan is working well? Do you see any ways to make it work better?
- How can we work together to make sure my child gets better (or stays well)?
- If I have questions about the treatment plan or my child’s care, who can I contact? How can I contact this person?
- Do you know the other people in my child’s network? Do you need any information from them to create my child’s treatment plan?
Questions to Ask Yourself Before Sharing Information

Before sharing information, asking yourself a few questions can help make sure you’re sharing the right information with the right people. You might want to ask yourself:

- Have we talked about how we’re going to communicate back and forth? If I share information, how will I get information back?
- How will this information be used?
- Who will this information be shared with?
- What consent forms are needed and which ones are in place?

Tips for Better Communication

When sharing and giving information, you can help everyone communicate better if you:

- Tell your child’s story so that others can picture who their child really is
- Connect people in your child’s network with each other
- Prepare for meetings
- Track where information is going

Looking at your child’s records lets you see what information is being shared and gives you a chance to make corrections. You can ask to see the following records at any time:

- Medical records from your child’s primary care provider.
- School records. It’s also a good idea to look at these when your child graduates, since the school records become your property after graduation.
- Therapy notes. It’s also a good idea to look at therapy notes when your child switches to a new therapist.
Tell Your Child’s Story

The more that people in your network know about your child, the stronger your connections will be. You may want to:

• Create a care map so you can show all the people in your child’s network (see page 149).

• Give out fact sheets and websites that have information about your child’s culture and diagnosis to those who work with your child.

• Create a notebook that has information about your child’s strengths and weaknesses, including hopes for the future.

• Create a “health-passport” about your child to share with your child’s network. A health passport contains important facts about your child.

Blank Health Passports on the Web

• For younger children, you can get a blank health passport at the Florida Center for Inclusive Communities website

• For youth, you can get a blank health passport at New Zealand Health and Disability Commissioner website

Connect People in Your Child’s Network

When you connect the people in your child’s network with each other, they get more comfortable working together. And when people are more comfortable with each other, it strengthens relationships and makes communication easier. You may want to:

• Set up meetings to let different people in your network get to know each other

• Bring others from the child’s network to your child’s visits with the primary care provider, school, and behavioral health provider

• Create a contact list of the people in your child’s network that you can share with others (see page 156)
Prepare for Meetings

Preparing for meetings helps you get the information you need, because it shows others that you are taking an active role in your child’s care and helps build trusting relationships. To prepare for meetings, you may want to:

- Make a list of the questions you want to ask your child’s school and providers before the meeting. Check off each one as you talk about it. If you don’t feel comfortable talking about an issue, you can always write a note.
- Learn about student rights and protections for students with an Individualized Education Plan (IEP). This information can be helpful if you’re meeting about a problem with school services.
- Bring information you may have received from consultants hired to complete a behavioral health assessment or IEP to your meetings.

Help Others Picture Your Child

Schools and providers work with many children. When you help them see who your child is, you build a stronger connection. You may want to:

- Put photos of your child on the table during meetings
- Bring your child to meetings

Track Where Information Is Going

When you keep records about where information is going, it helps you understand who needs information and if they have consent. You may want to:

- Keep a notebook to track the release forms you’ve signed.
- Write letters or emails to people in your child’s network. This gives you a record of what you agreed to.
- Create a communication book your child brings to school so you can write notes to the school and the school can write back to you.
Protecting Your Child’s Privacy

To protect your child’s privacy, you may want to:

- Take blank consent forms to your meetings, or ask your child’s school and providers if they have consent forms they want you to use. See pages 119 to 128 for sample consent forms.
- Share only the information needed to treat, educate, or keep your child safe.
- Ask others to keep the information you give them private. You can always say, “This information is private and I want to make sure it’s kept that way.” Say “no” to anyone who asks for information they don’t have a right to see, then explain the boundaries you set on sharing information.
- Make sure you read everything you sign. If you don’t understand something you read, ask someone to help you.

Email Is Not Secure

Email can be a great way to communicate, but it is not secure. When sending private information to someone, it’s best to avoid email.

Sharing Information with SBHCs

Remember that when you share information with a school based health center (SBHC), it’s the same as sharing information with any other health care provider. For example, you need to use the same communication channels with an SBHC as you would with the child’s primary care provider. For more information about SBHCs, visit the Massachusetts Association for School-Based Health Care website.
Supporting the Transition to Adulthood

As children get older, they may take on the main role in communicating with their network. This is a success to be celebrated — your child is growing up. For both you and your child, it’s helpful to know how your roles will change and how to help your child understand consent.

How Your Role Will Change

Your child will become a part of decision making and information sharing. Your providers will start to talk your child more about your child's health needs and communication:

- Some adolescent health services are kept private. Youth may make private decisions about pregnancy, family planning, and testing and treatment for sexually transmitted diseases. For more information, visit the American College of Gynecology website.
- Providers may start asking you and your child to sign consent forms before age 18. This helps your child learn more about privacy and communication.
- At age 18 and older, your child can sign their own consent forms.
- At age 18 and older in Massachusetts, your child has the right to talk to providers without your consent, unless a court decides they need a guardian. Even with a guardian, youth need to take part in decisions about sharing health information, if they’re able to.

Helping Your Child Understand Consent

The earlier you start talking to your child about consent and information sharing, the better prepared your child will be to take on new roles. You may want to:

- Ask your child to take part in making decisions about health communication from an early age.
- Talk to your providers about adolescent privacy, and make sure they’re taking time to speak with your adolescent child alone, without any family members.
- Make sure your adolescent knows what information will be kept private and what can be shared. If you’re not sure, you and your child can ask your provider. Generally, information can be shared without consent if your child is in danger or might harm someone else.
Chapter 5

At a Glance

Who’s this chapter for?
This chapter is for primary care providers and the staff at primary care practices.

What’s this chapter about?
This chapter gives best practices for primary care providers who want to:
• Build trusting relationships
• Get and share the right information
• Protect patient privacy
• Support youth in the transition to adulthood

How can primary care providers build trusting relationships?
To build trusting relationships with families, primary care providers can:
• Make the family part of team
• Respect privacy and consent
• Keep families informed

To build trusting relationships with schools and behavioral health providers, they can:
• Work out the best way to communicate and use that way all the time
• Respond to questions when asked for information
• Share information about the child that others need to know

How can primary care providers support privacy and communication?
To support communication and respect for privacy, primary care providers can:
• Always ask for consent to share information
• Give families and youth information they can understand and act on
• Use standardized consent forms and tell the family what they’re consenting to
Tips for Building Trust

Sharing information works best when the child’s network is built on honest and trusting relationships. Developing relationships takes time, but there are clear steps you can take to build trust with families, schools, and behavioral health providers.

Building Trust with the Child, Youth, and Family

When working with families, ask questions instead of making judgments — every family has its own stories and challenges. Families want to be heard and respected. It helps to show them that you’re connected, committed, and passionate about their child’s well-being.

To build trusting relationships with the family, you can:

- Make the family part of the team
- Respect privacy and the limits of consent
- Keep families informed

Make the Family Part of the Team

- Learn about a child’s culture, diagnosis, and related details before meeting with the family.
- Ask the family how they see the problem, what ideas they have for solving it, and what they want from you.
- Tell the family about strengths you see in the child.
- Remember that the family and youth have the final say in all decisions. Make sure they’re part of treatment plan discussions and decisions.
- Make sure the family or youth knows how to contact you, and who else to contact when you can’t be reached.
- Show teens that you’re interested in their well-being. Before you ask them for anything, tell them what information you’ll have to share and what stays private.

To learn more about setting goals with a family, visit the National Institute for Children’s Health Quality website.
Respect Privacy and the Limits of Consent

- Explain why consent is necessary. This will make it clear what information you will share and who you will share it with.

- Give a basic overview of HIPAA. If the child is in school, you may also want to tell them about FERPA. Both laws are important for protecting privacy. See page 21 for information on HIPAA and FERPA.

- If you’re going to share information without getting consent, explain to the family what you’re sharing and who’s getting the information.

- Set privacy expectations at the first meeting. The family’s access to information will change as the child gets older. State laws protect an adolescent’s privacy, and parents need to know that.

- Always ask for an adolescent’s consent to talk to parents, even if you’ve asked before.

- Explain the boundaries of information sharing before the family or youth signs consent. They need to know that the information shared includes medications, diagnoses, and management plans. They also need to know that not all of their health information gets shared. For example, schools only get health information related to school performance and behavioral health management.

Keep Families Informed

- Families need transparency and openness. Deciding the right information to share or not share is a fine balance. Will the information be helpful or harmful? Sharing more is generally better.

- If you’re planning to leave a patient, inform families well in advance. The less turnover for a family, the better. If turnover can’t be avoided, families appreciate having more time to make changes.
Building Trust with the School Team

Again, a trusting relationship with the school makes it more likely you’ll get and share the right information. When working with schools:

- Contact the school nurse first, unless you have another contact in the school.
- Review communications with the school carefully. Remove any unrelated health or behavioral information.
- Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way all the time. Keep in mind that school staff are most likely available after the school day.

Each school has a different way of communicating with providers, and the right contact at the school depends on the child’s needs. School nurses may make the best contacts since they understand both medicine and education. They also have contact with the principal, the support team, and special education. School nurses may not attend all Individualized Education Plan (IEP) meetings, but they can still make sure the IEP team has all the information they need. They can also get information from the team to give to the child’s providers.

Building Trust with the Behavioral Health Team

Clear reasons and expectations can make all the difference in sharing and getting the information you need. When working with behavioral health providers:

“The first thing they need to know is why we are asking these questions. ‘I came to you for a headache; why are you asking me about school?’...Next, they need to know that we’re not about judgment. We are about service...If we want to build trust...we need to be explicit...we don’t want them to be angry at us when we suggest that we talk to their parents together. They are in control of that decision.”

—Kenneth R. Ginsburg, MD
• Explain why it’s important for you to see behavioral health records. For example, “When working with adolescents, I need access to this information because…”

• Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way all the time.

Getting and Sharing the Right Information
Getting and sharing the information you need often means asking the right questions. Because every family, provider, and school is different, there’s no one formula. Use the questions below for ideas about the kinds of things you may want to ask about.

Questions to Ask the Child, Youth, and Family

About Treatment

• How do you think that the treatment plan is working?

• Do you have any ideas for helping the treatment plan work better?

• Would you like to work together to create a crisis plan? A crisis plan helps you know what to do if your child has a health crisis.

About Consent and Boundaries

• To give your child the best care, here’s who I think I need to talk to. Do you have any questions about why talking to these people is important?

• Can I have your consent to share your information with…? Can I have your consent to get information from…?

• Is there any information that you don’t want me to share with…? Would you mind telling me why you don’t want this information shared?

• Do you have any questions about how I’ll keep your information private?
About School

- Does your child have an IEP or 504 (school education) plan? Can I have your consent to review that plan, so I can better care for the child? How can I get a copy of the plan?
- Who are the best people at the school to talk to about your child? What's the contact information for the school nurse and others at the school?
- Has your child had any psychological testing at the school? Will you give them your consent to share the test results with me?
- What services does your child get in the community and in the school? Will you give your consent to the community providers and schools to share that information with me?

About Behavioral Health

- Does your child have a treatment plan or a crisis plan from your child’s behavioral health provider? Will you give me your consent to look at the plan, so I can better care for the child? How can I get a copy of the plan?
- What's the contact information for your child’s behavioral health provider? What about for any other behavioral health specialists your child is seeing?

Questions to Ask the School Team

To Get the Information You Need

- Do you have any concerns about the child that you want to share?
- Can you think of anything that would help develop or improve the child or youth’s treatment plan? Have you asked for consent to share that information with me?
- Is there a school re-entry program I can share information with after hospitalization or absence? If so, who can I contact?
- Does the child have an IEP or 504 plan? Have you asked for consent to share that with me?
- What other services does the child receive at school?
- Has the school done any psychological testing? Have you asked the family for consent to share the results with me?
School Re-entry Programs

A student returning to school after a behavioral health or medical issue (such as a concussion) faces special challenges. Creating a school re-entry plan can be helpful to the student and everyone involved in the student’s care. Some schools in Massachusetts have re-entry programs where a coordinator creates a team to help ease the youth back into school.

Coordinators may:

- Provide clinical care
- Give support and information
- Help families negotiate the social service network
- Manage communication with health care providers and therapists
- Work with students, teachers, and tutors

For more information about school re-entry programs, visit:

- The [Metrowest Health Foundation](#) website
- The [Brookline Resilient Youth Team Program](#) website

To Share the Right Information

- Is there any information I can give you about the child’s medical care to help you develop or improve the school educational plan?
- Do you need any information from me to plan for:
  - Tutoring for a long medical absence
  - Chronic disease management (diabetes, asthma plans, medication adjustments, 504 planning)
  - Acute illness or injury management (like a concussion)
  - Preventive care (like immunizations)

Questions to Ask the Behavioral Health Team

General

- Do you have any concerns about the child that you want to share?
- Will you let me know when you receive my referral?
- Will you let me know when you start seeing the child?
• What’s important for me to know about the child’s behavioral health condition?
• Have there been any recent changes in the child’s behavioral health?

Medications
• What medications have you prescribed for the child?
• Will you manage the child’s behavioral health medications, or do you want me to do that? If you want me to do it, what’s important for me to know?
• Have there been any recent changes in medications?
• How is the child responding to the medications?

Treatment and Crisis Plans
• Have you asked the youth or family for consent to share the crisis plan with me and with the school?
• What is the child’s treatment plan? How do you think the plan is working?
• Have you asked the youth or family for consent to share your treatment plan with me and with the school?
• Have you developed a crisis plan with the family?
• Will you let me know if you change anything in the child’s treatment plan?

Questions to Ask Yourself Before Sharing Information
Before sharing information, ask yourself a few standard questions to help make sure you’re sharing the right information with the right people.

Protecting Privacy
• Have we talked about how we’re going to communicate back and forth? If I share information, how will I get information back?
• How will this information be used?
• Who will this information be shared with?
• Am I following HIPAA guidelines for this information?
Getting Consent

- Have I asked the youth or family about their boundaries on sharing information? Does sharing this information honor their boundaries?
- What consent forms are needed and which ones are in place?
- What can be done without parental consent, if necessary?

Sharing with the School

- What health information does the school need for the child’s education or safety?
- What health information is not needed by the school?

Tips for Better Communication in Your Practice

Bringing better communication into your practice can be complicated, but you can make a lot of progress by taking small steps. Making small changes can have a big impact over time, especially in the following areas:

- Patient education
- Standardized forms
- Web and electronic tools
- Care coordination

Patient Education

Families need information they can use and act on. To best support the families you work with:

- Use Google or other online tools to translate patient education materials in the family's native language. This may be easier than keeping a number of materials in other languages at your practice.
- Ask families how they learn best (talking, in writing).
- Use pictures and graphics to explain health topics like asthma.
- Give out after-visit sheets, including sheets with health care guidance after well-visits. Circle the most important information.
- Provide families with a portable medical record and summary. This is part of some electronic health records (EHR). See page 114 for an example of a portable medical summary.
• Provide fact sheets on applicable diseases.
• Create shared drives with helpful health materials, so your staff can print information useful to youth and family.

**Standardized Forms**

Use standardized forms to share and ask for information. It makes getting consent easier for you and for the family. Try some of the following in your practice:

• Put Release of Information forms in every exam room. Fill them out with the patient in the room.
• Use two-way communication forms so information can be shared between two groups. You can then ask for consent to share information between your practice and behavioral health providers or other teams.
• Use standardized sports clearance forms and medication order forms (often in a practice’s Electronic Health Record) so you don’t have to write new letters every time. You can always add specific information to these form letters to customize them.
• Use a form to give your input to the IEP and 504 process, or when asking for an IEP.
• Individualized Health Plans (IHP) are created by the family, school nurse, and health care providers. An IHP has important information about the child’s health care needs while in school.18

You can read a sample IHP at the PACER Center website.

**Web and Electronic Tools**

Web-based and electronic tools make it easier to communicate and track information. You can:

• Create a secure website or portal for two-way sharing. Many practices have created patient portals so that they can communicate with patients in private. Portals are secure, they can be used at any time of day, and they support effective communication.
• Use technology such as Skype or Face Time to allow you to see the people you are talking with.
Assign Care Coordination Tasks to Staff

Care coordination tasks help to manage communication for a patient’s care. Tasks include:

- Knowing who to communicate with
- Making sure that consent forms are signed
- Checking that contact information is correct
- Following up with the family, providers, and schools to make sure you get information back

Someone doing care coordination tasks in your practice can make strong communication a reality. Even if you don’t have a care coordinator at your practice, this responsibility can be shared by other staff, like a Medical Assistant or one of your front desk staff.

Protecting Privacy in Your Practice

Privacy is the responsibility of everyone working in your practice. Here are some tips for creating a culture that respects patient privacy.

Training and Policies

- Teach your staff about HIPAA and privacy
- Create and follow written policies and agreements for communication between your practice and other members of the child’s network
For Children Under Age 18

- Educate youth and parents about privacy for youth, starting before adolescence.¹⁹
- Interview patients without their parents by age 14, or an age appropriate for the child.
- Explain to adolescents that some information they share with you may have to be shared with their parents, while other information can be kept private.
- As youth participate more in their care as they get older, providers can ask for the youth’s signature on consent forms before age 18, depending on the readiness of the youth (assent to consent). This is an example of assisting the youth to take responsibility for their care as they transition to adulthood.
- Include a school release form in new patient materials and at every well child exam, so that the family or youth can sign it and return to you.

For Children Age 18 and Older

- When children turn age 18, ask them for new releases to get and share information with schools and providers — the ones signed by their parents will no longer be valid
- If a child over age 18 gives consent for family involvement, get a release to speak with family members
- Request proof of guardianship for families of children age 18 and older with intellectual disabilities
- Include a school release form in new patient materials and at every well child exam, so that the family or youth can sign it and return to you
- Include a behavioral health provider release form in new patient materials and at every well child exam, so that the family or youth can sign it and return to you

Sharing with Schools and Behavioral Health Providers

Share only what the school or behavioral provider needs to know for the child’s safety, educational, or behavioral health needs.
Email Is Not Secure
Email can be a great way to communicate, but it is not secure. When sending private information to someone, it’s best to avoid email.

Sharing Information with SBHCs
Remember that when you share information with a school based health center (SBHC), it’s the same as sharing information with any other health care provider. For more information about SBHCs, visit the Massachusetts Association for School-Based Health Care website.

Supporting the Transition to Adulthood
The transition to adulthood is a success to be celebrated — youth are growing up. It can also be a challenge to manage. As a primary care provider, you’re in a unique position to help with health care transition planning. Health care transition is the process of:

- Preparing youth for adulthood
- Understanding and supporting youth in their goals
- Transferring care (when necessary) to adult providers

Youth may make a number of transitions at different times. For example, they may transition to a new behavioral health provider at a different age than to a new primary care provider. Also, their health care transition may be separate from their transition from high school to college or work.

You can support youth and families by developing a transition plan with them, helping them to share the right information, and creating an office policy for transition to adulthood.

Develop a Transition Plan
Every youth needs an individual plan to help them meet their transition goals. All youth have unique strengths and challenges, so the transition plan will be different in every case. You can help them look at strengths and needs in areas such as:
- Medication management
- Understanding medical terms and diagnoses
- Making medical appointments
- Understanding insurance
- Maintaining social networks
- Participating in household life
- Developing skills to make sound health decisions
- Learning about giving consent to share information (See tip on assent to consent above)

**Help Share the Right Information**

Youth in transition may need to decide what information to share with new providers. You can help youth and families develop a portable medical summary or care plan. This is a one- or two-page document with key health information, such as allergies, medications, and diagnoses. Make sure to include youth in developing and updating their own health summaries.

**Create an Office Policy for Transition**

The American Academy of Pediatrics recommends that every pediatric practice have a clear transition policy. A transition policy needs to be:

- Complete — giving your practice’s ideas around adolescent care, not just general statements like “transfer to adult team”
- Specific — listing specific ages and what happens when
- Made available to all patients — on your website, in brochures, and posted at front desk

See page 138 for a sample transition policy.
Who’s this chapter for?
This chapter is for behavioral health providers.

What’s this chapter about?
This chapter gives best practices for behavioral providers who want to:

• Build trusting relationships
• Get and share the right information
• Protect patient privacy
• Support youth in the transition to adulthood

How can behavioral health providers build trusting relationships?
To build trusting relationships with families, behavioral health providers can:

• Make the family part of the team
• Respect privacy and the limits of consent
• Keep families informed

To build trusting relationships with schools and primary care providers, they can:

• Work out the best way to communicate and use that way all the time
• Respond to questions when asked for information
• Share information about the child that others need to know

How can behavioral health providers support privacy and communication?
To support better communication and respect for privacy, behavioral providers can:

• Use standardized forms for consent and information sharing
• Share only what schools and primary care providers need to know to keep the child safe and help meet educational or behavioral health needs
• Create special contracts with youth about sharing information with parents
Tips for Building Trust
Sharing information works best when the child’s network is built on honest and trusting relationships. Developing relationships takes time, but there are clear steps you can take to build trust with families, primary care providers, and schools.

Building Trust with the Child, Youth, and Family
When working with families, ask questions instead of making judgments — every family has its own stories and challenges. Families want to be heard and respected. It helps to show them that you’re connected, committed, and passionate about their child’s well-being.

To build trusting relationships with the family, you can:

- Make the family part of the team
- Respect privacy and the limits of consent
- Keep families informed

Make the Family Part of the Team
- Learn about a child’s culture, diagnosis, and related details before meeting with the family.
- Ask the family how they see the problem, what ideas they have for solving it, and what they want from you.
- Tell the family about strengths you see in the child.
- Make sure the family and youth are part of treatment plan discussions and have a say in all decisions.
- Make sure the family or youth knows how to contact you, and who else to contact when you can’t be reached.
- Show teens that you’re interested in their well-being. Before you ask them for anything, tell them what information you’ll have to share and what stays private.

Respect Privacy and the Limits of Consent
- Explain why consent is necessary — consent makes it clear what information will be shared and who can get the information.
- Give a basic overview of HIPAA. If the child is in school, you may also want to tell them about FERPA. Both laws are important for protecting privacy. See page 21 for information about HIPAA and FERPA.
• If you’re going to share information without getting consent, explain to the family what you’re sharing and who’s getting the information.

• Set privacy expectations at the first meeting. The family’s access to information will change as the child gets older. State laws protect an adolescent’s privacy, and parents need to know that.

• Ask youth under age 18 for consent to talk to parents, even if you’ve asked before.

• Explain the boundaries of information sharing before the family or youth signs consent. They need to know that the information shared includes medications, diagnoses, and management plans. They also need to know that not all of their health information gets shared. For example, schools may only get health information related to school performance and behavioral health management.

Keep Families Informed

• Families need transparency and openness. Deciding the right information to share or not share is a fine balance. Will the information be helpful or harmful? Sharing more is generally better.

• If you’re planning to leave, inform families well in advance. The less turnover for a family, the better. If turnover can’t be avoided, families appreciate having more time to make changes.

Building Trust with Primary Care Providers

Clear expectations make all the difference when giving and receiving information. When working with primary care providers:

• Remind them about the kinds of information that can and can’t be shared

• Let them know about the behavioral health goals

• Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way consistently.

Building Trust with the School Team

Again, a trusting relationship with the school makes it more likely you’ll get and share the right information. When working with schools:

• Find out who to use as your main contact at the school. It may be the school nurse or the school psychologist.
• Review communications to the school carefully. Remove any unrelated information, such as information about other family members.

• Let the school know what they can do to help meet the behavioral health goals.

• Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way consistently. Keep in mind that school staff are most likely available after the school day.

Each school has a different way of communicating with providers, and the right contact at the school depends on the child’s needs. School nurses may make the best contacts since they understand both medicine and education. They also have contact with the principal, the support team, and special education. School nurses may not attend all Individualized Education Plan (IEP) meetings, but they can still make sure the IEP team has all the information they need. They can also get information from the team to give to the child’s providers.

Getting and Sharing the Right Information

Getting and sharing the information you need often means asking the right questions. Because every family, provider, and school is different, there’s no one formula. Use the questions below for ideas about the kinds of things you may want to ask about.

Questions to Ask the Child, Youth, and Family

About Treatment

• How do you think the treatment plan is working?

• Do you have any ideas for helping the treatment plan work better?

• Would you like to work together to create a crisis plan? A crisis plan helps you know what to do if your child has a behavioral health crisis.

About Consent and Boundaries

• To give your child the best care, here’s who I think I need to talk to. Do you have any questions about why talking to these people is important?

• Can I have your consent to share your information with…? Can I have your consent to get information from…?
• Is there any information that you don’t want me to share with…? Would you mind telling me why you don’t want this information shared?
• Do you have any questions about how I’ll keep your information private?

About School
• Does your child have an IEP or 504 (school education) plan? Can I have your consent to review that plan, so I can better care for the child? How can I get a copy of the plan?
• Who are the best people at the school to talk to about your child? What’s the contact information for the school nurse and others at the school?
• Has your child had any psychological testing at the school? Will you give them your consent to share the test results with me?
• What services does your child get in school? Will you give your consent to the school to share that information with me?

About Medical Care
• What’s the contact information for your child’s primary care provider? What about for any other specialists your child is seeing?
• Have there been any changes in your child’s health?
School Re-entry Programs

A student returning to school after a behavioral health or medical issue (such as a concussion) faces special challenges. Creating a school re-entry plan can be helpful to the student and everyone involved in the student’s care. Some schools in Massachusetts have re-entry programs where a coordinator creates a team to help ease the youth back into school.

Coordinators may:

- Provide clinical care
- Give support and information
- Help families negotiate the social service network
- Manage communication with health care providers and therapists
- Work with students, teachers, and tutors

For more information about school re-entry programs, visit:

- The Metrowest Health Foundation website
- The Brookline Resilient Youth Team Program website

Questions to Ask the Primary Care Team

General
- Do you have any concerns about the child that you want to share?
- What’s important for me to know about the child’s medical condition?
- Have there been any recent changes in the child’s health?

Medications
- What medications have you prescribed for the child?
- Have there been any recent changes in medications?
- How is the child responding to the medications?

Treatment and Crisis Plans
- What is the child’s treatment plan? How do you think the plan is working?
• Have you asked the youth or family for consent to share your treatment plan with me and with the school?
• Will you let me know me if you change anything in the child’s treatment plan?
• Have you developed a crisis plan with the family?
• Have you asked the youth or family for consent to share the crisis plan with me and with the school?

Questions to Ask the School Team

About Treatment
• Do you have any concerns about the child that you want to share?
• Can you think of anything that would help develop or improve the child or youth’s treatment plan? Have you asked for consent to share that information with me?
• Has the school done any psychological testing? Have you asked the family for consent to share the results with me?
• What other services does the child receive at school?

About the School
• Is there a school re-entry program I can share information with after hospitalization or absence? If so, who can I contact?
• Does the child have an IEP or 504 plan? Have you asked for consent to share that with me?
• Is there any information I can give you about the child’s behavioral health care to help you develop or improve the school educational plan?
• Do you have psychological testing results?
• What are the school’s systems for communicating with health care and behavioral health providers? If there’s no system in place, can we set one up or make a plan for routine communication?
Questions to Ask Yourself Before Sharing Information

Before sharing information, asking yourself a few standard questions can help make sure you’re sharing the right information with the right people.

Protecting Privacy
- Have we talked about how we’re going to communicate back and forth? If I share information, how will I get information back?
- How will this information be used?
- Who will this information be shared with?
- Am I following HIPAA guidelines for this information?

Getting Consent
- Have I asked the youth or family about their boundaries on sharing information? Does sharing this information honor their boundaries?
- What consent forms are needed and which ones are in place?
- What can be done without parental consent, if necessary?

Sharing with the School
- What health information does the school need for the child’s education or safety?
- What health information is not needed by the school?

Tips for Better Communication

When sharing and giving information, you can help everyone communicate better if you:
- Use standardized forms
- Help tell the child’s story
- Hold face-to-face meetings

Use Standardized Forms

Standardized forms make getting consent and sharing information easier for you and for the family. You might want to try using two-way communication forms. These
forms allow information to be shared between two groups. You can then ask for consent to share information between yourself and the primary care practice or other teams.

**Help Tell the Child’s Story**

You can write a plain language narrative or summary about the child to share with the child’s network. By writing a clear summary, you can help more people better understand what the child is experiencing and how they can help.

For example, a bio-psychosocial assessment is a narrative that’s usually filled with social worker jargon. By writing a plain language version, you can help people in the child’s network understand:

- History of concerns
- Family background
- Degree of functioning
- Mental status exam results
- Risk assessment results
- DSM V diagnosis

**Hold Face-to-Face Meetings**

People are better at sharing information when they meet face-to-face. Tone and body language help communicate more than a phone call or email. If face-to-face meetings are not possible, then think about using technology such as Skype or Face Time.

**Protecting Privacy**

To help protect privacy, you can:

- Make sure there are signed consents for sharing information. Informed consent and good standardized consent forms make it clear who can get information and who owns the information.
- Take privacy training given by your organization.
- Share only what the PCP and school need to know to keep the child safe and help meet educational or behavioral health needs. Only information related to the child’s health or school performance gets shared.
• Create special contracts with youth about sharing information with parents. Youth need to know that information may need to be shared with parents if there are violence or safety issues.

• Make sure that private information about other family members is not shared. Only share relevant information.

**Email Is Not Secure**

Email can be a great way to communicate, but it is **not** secure. When sending private information to someone, it’s best to avoid email.

**Sharing Information with SBHCs**

Remember that when you share information with a school based health center (SBHC), it’s the same as sharing information with any other health care provider. For example, you need to use the same communication channels with an SBHC as you would with the child’s primary care provider. For more information about SBHCs, visit the [Massachusetts Association for School-Based Health Care](#) website.

**Supporting the Transition to Adulthood**

The transition to adulthood is a success to be celebrated — youth are growing up. It can also be a challenge to manage. Youth often appreciate it when you:

• Help them understand what information gets shared and who it gets shared with.

• Ask them to take part in deciding what information gets shared and who it gets shared with.

• Ask them how well they understand their diagnoses, treatment plan, and future treatment options.

• Help them and their families understand if they will still need a guardian, either full or limited.

• Sign new contracts or agreements with them when they turn age 18. At age 18, most youth become the main decision makers for their health care.
Who’s this chapter for?
This chapter is for schools, including education staff, school health services, and behavioral health supports.

What’s this chapter about?
This chapter gives best practices for school staff who want to:
- Build trusting relationships
- Get and share the right information
- Protect student privacy
- Support youth in the transition to adulthood

How can schools build trusting relationships?
To build trusting relationships with families, school staff can:
- Make the family part of the team
- Respect privacy and consent
- Keep families informed

To build trusting relationships with behavioral health providers and primary care providers, they can:
- Find the best way to communicate and use that way all the time
- Respond to questions when asked for information
- Share information about the child that others need to know

How can schools support privacy and communication?
To support better communication and respect for privacy, school staff can:
- Help others connect with the school
- Talk to family and youth about consent
- Share the behavioral plans used for classroom management
Tips for Building Trust

Sharing information works best when the child’s network is built on honest and trusting relationships. Developing relationships takes time, but there are clear steps you can take to build trust with families and providers.

Building Trust with the Child, Youth, and Family

When working with families, ask questions instead of making judgments — every family has its own stories and challenges. Families want to be heard and respected. To build trusting relationships with the family, you can:

- Make the family part of the team
- Respect privacy and the limits of consent
- Keep families informed

Make the Family Part of the Team

- Learn about a child’s culture, diagnosis, and related details before meeting with the family. When you know how to best meet the child’s learning needs and challenges, you get the relationship off to a great start.
- Ask the family how they see the problem, what ideas they have for solving it, and what they want from you.
- Tell the family about strengths you see in the child.
- Remember that the family and youth have the final say in all decisions. Make sure they’re part of education discussions and decisions.
- Make sure the family and youth know who to contact at the school and how to contact them for different needs. They also need to know who to get in touch with if the main contacts can’t be reached.

Respect Privacy and the Limits of Consent

- Explain why consent is necessary — consent makes it clear what information will be shared and who can get the information.
- Set privacy expectations at the first meeting. The family’s access to information will change as the child gets older. State laws protect an adolescent’s privacy, and parents need to know that.
- Explain the boundaries of information sharing before the family or youth signs consent.
Keep Families Informed

- Families need transparency and openness. Deciding the right information to share or not share is a fine balance. Will the information be helpful or harmful? Sharing more is generally better.
- Set up a meeting with families of children new to your school before the start of the school year. That way, you and the family can create a relationship and agree on a plan of care for the year.
- Especially at the end of each school year, set up a meeting to talk about changes from one grade to the next. It’s important to discuss the child’s needs and show the family that information is being shared with the next grade’s teachers and staff.

Building Trust with Primary Care Providers

Clear reasons and expectations can make all the difference in sharing and getting the information you need. When working with primary care providers:

- Tell them about the kinds of information that can and can’t be shared
- Let them know about educational goals
- Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way all the time

Building Trust with the Behavioral Health Team

Again, a trusting relationship with behavioral health providers makes it more likely you’ll get and share the right information. When working with behavioral health providers:

- Tell them about the kinds of information that can and can’t be shared
- Let them know about educational goals
- Choose a way to communicate that works best for everyone — from the right technology (fax, email, phone, text) to the best times to communicate — and use that way all the time
Getting and Sharing the Right Information

Getting and sharing the information you need often means asking the right questions. Because every family and provider is different, there’s no one formula. Use the questions below for ideas about the kinds of things you may want to ask about.

Questions to Ask the Child, Youth, and Family

About Education Plans

• How do you think the Individualized Education Plan (IEP) or 504 (school education) plan is working?

• Do you have any ideas for helping the IEP or 504 plan work better?

About Consent and Boundaries

• To give your child the best care, here’s who I think I need to talk to. Do you have any questions about why talking to these people is important?

• Can I have your consent to share your information with…? Can I have your consent to get information from…?

• Is there any information that you don’t want me to share with…? Would you mind telling me why you don’t want this information shared?

• Do you have any questions about how I’ll keep your information private?

About Medical and Behavioral Health

• Have there been any recent changes in your child’s health that I need to know about? Any changes in your child’s social situation?

• Has your child had any recent hospitalizations? If so, what was the reason and outcome?

• What’s the contact information for your child’s behavioral health provider? What about for your child’s primary care provider? And any other specialists your child is seeing?

• What about school has been difficult for your child? What does your child do to cope with that?

• What helps calm your child down in a crisis?
Questions to Ask the Primary Care Team

About Health and Learning

- Do you have any concerns about the child that may impact the child’s success at school?
- What’s important for me to know about the child’s medical condition?
- Have there been any recent changes in the child’s health?
- Does the child have any allergies?

About Medications

- What medications is the child taking?
- Have there been any recent changes in medications?
- How is the child responding to the medications?

About Treatment and Crisis Plans

- What is the child’s treatment plan? How do you think the plan is working?
- Have you asked the youth or family for consent to share your treatment plan with me?
- Will you let me know me if you change anything in the child’s treatment plan?
- Have you developed a crisis plan with the family?
- Have you asked the youth or family for consent to share the crisis plan with me?
- If the child is hospitalized, how can we best support the child’s re-entry into the school?
- Can you provide documentation to support a lengthy absence from school? Can you provide documentation to support tutoring during that absence?

Questions to Ask the Behavioral Health Team

About Behavioral Health

- Do you have any concerns about the child that may impact the child’s success in school?
- Can you provide written clearance for the child to return to school after a suicide attempt?
- What warning signs for depression should we look for?
• What de-escalation strategies work for this child?
• Does the crisis plan include the school?

About Medications
• What medications have you prescribed for the child?
• Have there been any recent changes in medications?
• How is the child responding to the medications?

About Treatment and Crisis Plans
• Have you asked the youth or family for consent to share your treatment plan with me?
• What is the child’s treatment plan? How do you think the plan is working?
• How can the school help make the plan successful?
• Have you developed a crisis plan with the family?
• Have you asked the youth or family for consent to share the crisis plan with me?
• How can the school help avoid a crisis?

Questions to Ask Yourself Before Sharing Information

Before sharing information, asking yourself a few standard questions can help make sure you’re sharing the right information with the right people.

Protecting Privacy
• Have we talked about how we’re going to communicate back and forth? If I share information, how will I get information back?
• How will this information be used?
• Who will this information be shared with?
• Am I following FERPA guidelines for this information?

Getting Consent
• Have I asked the youth or family about their boundaries on sharing information?
  Does sharing this information honor their boundaries?
• What consent forms are needed and which ones are in place?
• What can be done without parental consent, if necessary?

Sharing with Other School Staff and with Providers
• Is this health information needed for the child’s education or safety? (If not, the information should not be shared).
• What health information is not needed and should be removed?

Tips for Better Communication
When sharing and giving information, you can help everyone communicate better if you:
• Help others connect with the school
• Support information sharing

Help Others Connect with the School
It may not always be clear to families, providers, and others in the child’s network who they can contact at the school for different needs. You can make it easier for them by:
• Reaching out to behavioral health providers and others in the child’s network to more easily share information about the child.
• Create a short document about the school that gives key contacts and hours of operation. You can give this information to providers and others in the child’s network.
• Provide information about school re-entry programs.

Support Information Sharing
Some of the ways you can support information sharing in a child’s network include:
• Sharing student information and giving support through the school’s Student Assistance Teams. Teams may include a school nurse, school psychologist, vice principal, Special Education (SPED) teacher, and guidance counselor. They help students and staff with communication and privacy.
• Linking your communication systems to other providers.
• Share the behavioral plans you use for classroom management with others in the child’s network.
Protecting Privacy

To help protect a student’s privacy, you can:

- Remind providers and families that email is not a private system — email can’t be trusted for sharing health information. They can give health information to the school nurse by phone, letter, or fax.
- Talk about consent with the youth and family.
- Make sure you get a signed release to speak with the child’s primary care provider and behavioral health provider.

Email Is Not Secure

Email can be a great way to communicate, but it is not secure. When sending private information to someone, it’s best to avoid email.

Sharing Information with SBHCs

Remember that when you share information with a school based health center (SBHC), it’s the same as sharing information with any other health care provider. For example, you need to use the same communication channels with an SBHC as you would with the child’s primary care provider.
Supporting the Transition to Adulthood

The transition to adulthood is a success to be celebrated — youth are growing up. It can also be a challenge to manage.

Massachusetts law requires schools to create a transition plan for any child on an IEP, starting at age 14. Keep in mind that:

- All members of the child’s network need to know the activities and goals in the transition plan
- All members in the child’s network need to make sure that the transition plan covers medical and safety concerns
- Students age 14 and older must be invited to IEP meetings where transition planning is discussed

To learn more about supporting the transition to adulthood, visit the Massachusetts Department of Elementary & Secondary Education website, where you can also find a sample Transition Planning Form.
Acknowledgments

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Thank you to everyone who tested and contributed to the Guide!
References


4 M.G.L. c. 112, § 12E; M.G.L. c. 111, §§ 24E, 117.

5 M.G.L. c. 123, § 10.

6 Thorpe and Rosenbaum, “EPSDT and Health Information.”

7 45 CFR, section 164.508A2 and 45 CFR, section 160.203c.112 s.12F.


12 From the Care Coordination Task Force, “Framework for Defining High-Performing Pediatric Care Coordination” Funded by the Centers for Medicare and Medicaid Services (CMS) through grant funds issued pursuant to CHIPRA section 401(d), 2014), 2-3.


16 Patricia A Levesh, Esq., Greater Boston Legal Services.


Appendix A: Laws and Regulations

Summary of Laws

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| The Health Insurance Portability and Accountability Act of 1996 (HIPAA) | For primary care providers, behavioral health care providers and patients  
Covers exchange of information between providers and provides patients rights around exchange of information |
| Family Educational Rights and Privacy Act (FERPA)                   | Applies to educational entities and anyone receiving federal Department of Education funds.  
Covers the release of information from a student’s educational record |
| Individuals with Disabilities Education Act (IDEA)                 | Covers states and localities                                                                                                                                 |
| Title 42 Code of Federal Regulations, Part 2                        | Covers federally assisted alcohol and drug programs  
Covers the rules around release of information by these programs |
| Protection of Pupil Rights Amendment (PPRA)                         | Applies to educational institutions  
Relates to student participation in certain surveys |
| Massachusetts General Laws chapter 112 | Sections 12 E and S  
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Consent to treatment |
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|                                      | Section 129A  
M.G.L. chapter 112, section 129A  
Psychologists and clients communication (and MGL Chapter 233, section 20 B exception to Section 129 A)  
M.G.L. chapter 233, section 20B |
|                                      | Sections 135 A and B  
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| General Laws, chapter 111 | Sections 70 F and G  
M.G.L. chapter 111, section 70F  
M.G.L. chapter 111, section 70G  
Health care providers and confidentiality of HIV and genetic testing |
| General Laws, chapter 123 | Section 36 B Licensed Mental Health Professionals obligation to report information  
M.G.L. chapter 123, section 36B |
| General Laws, chapter 93H | M.G.L. Chapter 93H  
Protection of personal information of MA residents |
| Regulations               | Department of Public Health  
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Licensed substance abuse programs (confidentiality of records) |
|                          | Department of Mental Health  
Department of Mental Health  
Mental health facilities (confidentiality of records) |
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<td>Board of Registration of Allied Mental Health and Human Services Professionals Advisory Policy on Distance, Online, and Other Electronic-Assisted Counseling</td>
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<td>Board of Registration of Psychologists Advisory Practicing with children and families in Massachusetts where parents may be separate, divorced, or never married</td>
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Federal Laws

1. The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPAA Privacy Rule

The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, was enacted on August 21, 1996. The Privacy Rule was initially published in 2000 and then later updated in 2003 and 2013. (Thorpe and Rosenbaum, Understanding the Interaction between EPSDT and Federal Health Information and Privacy and Confidentiality Laws, Sept 2013, p. 10)

The HIPAA Privacy Rule provides federal protections for health information, gives patients rights for sharing the information and makes rules for who and how others can receive the information.

Under HIPAA, health care providers are able to share certain information with other health care providers, without patient consent, when necessary for treatment of the patient. Providers are bound to share only that information that is ‘minimally necessary’ for the purpose that the information is being shared. However, as noted elsewhere in this Guide, it is always best for health care providers to talk to families about the need for sharing information, and obtaining consent for that sharing.

HIPAA Security Rule

In 2009, new legislation was enacted dealing with health information technology and providing privacy and security standards for an individual’s health care record. The Health Information Technology for Economic and Clinical Health (HITECH) Act was enacted under the American Recovery and Reinvestment Act on February 17, 2009. Under HITECH, covered entities (defined to include health care providers, health plans and health care clearinghouses) must ensure the confidentiality, integrity and availability of all electronic protected health information that the covered entity (or a business associate) creates, receives, maintains or transmits.

For More Information

HIPAA summaries are available online at the U.S. Department of Health and Human Services website and the Bazelon Center for Mental Health Law:

- HHS General Summary
- HHS Privacy Summary
- Bazelon HITECH Summary

The Massachusetts Department of Health and Human Services has answers to Frequently Asked Questions on HIPAA and School Health.

American Medical Association has information to help physicians comply with HIPAA rules: HIPAA: Health Insurance Portability and Accountability Act

US Dept of HHS Office for Civil Rights has information about sharing information for a patient being treated for a mental health condition: HIPAA Privacy Rule and Sharing Information Related to Mental Health Guidance

2. Family Educational Rights and Privacy Act (FERPA)

FERPA protects the privacy of students’ “education records.” FERPA applies to educational agencies and institutions that receive funds under any program administered by the U.S. Department of Education. The FERPA law does not apply to private schools.

For purposes of this Guide, we will call these entities “schools”. A school may not have a policy or practice of disclosing the education records of students, or personally identifiable information from education records, without a parent or eligible student’s written consent.

At the elementary or secondary level, educational records include:

- A student’s health records, including immunization records, maintained by the school
- Records maintained by a school nurse
- Records that schools maintain on special education students, including records on services provided to students under the Individuals with Disabilities Education Act (IDEA)

When a medical clinic is operating at a school, whether FERPA or HIPAA rules apply to the clinic’s records depends on whether the clinic is carrying out responsibilities of the school, under an agreement with the school. If it is, then FERPA laws apply. If not, then HIPAA laws apply. (Thorpe and Rosenbaum,
Under FERPA, parents and eligible students have the right to inspect and review the student’s education records and to seek to have them amended in certain circumstances.

For More Information

The FERPA law: Department of Education. Family Educational Rights and Privacy; Final Rule. 20 U.S.C. § 1232g; 34 CFR Part 99. This link contains a summary of FERPA.


3. Individuals with Disabilities Education Act (IDEA)

“The Individuals with Disabilities Education Act (IDEA) finances educational and early intervention (EI) services for infants, toddlers and pre-school aged children….. Health records maintained by schools or their agents such as a school nurse or other health practitioner working for or under contract with a school (are) subject to the FERPA standard, and shielded from disclosure to third parties (including…the providers) without written consent, except in narrow circumstances. Similar standards apply to EI services; safeguards must be in place to insure the confidentiality of personally identifiable information.” (20 U.S.C. section 1439(a)(2))

(Excerpted from Thorpe and Rosenbaum, Understanding the Interaction between EPSDT and Federal Health Information and Privacy and Confidentiality Laws, Sept 2013, p 19.)

The Part C of the IDEA funds education/early intervention services for infants and toddlers through age 2 who have developmental delays or who have been diagnosed with physical or mental impairments likely to lead to development delays. Part B of the IDEA ensures that children with disabilities ages 3-21 receive special education and related services in school.
Though IDEA is a federal law, Massachusetts has enacted a law, and promulgated regulations governing special education in the Commonwealth. The Massachusetts law is codified in Massachusetts General Law Chapter 71B. The related state regulations are available in the Code of Massachusetts Regulations at 603 C.M.R 28.


In the substance abuse field, confidentiality is governed by federal law (42 United States Code. § 290dd-2) and associated regulations (42 Code of Federal Regulations, Part 2). This law and these regulations outline under what limited circumstances information about the client’s treatment may be disclosed with and without the client’s consent.

42 C.F.R., 2 applies to all records relating to the identity, diagnosis, prognosis, or treatment of any patient in a substance abuse program that is conducted, regulated, or directly or indirectly assisted by any department or agency of the United States. It applies to any program that:

1) holds itself out as providing, and provides, alcohol or drug abuse diagnosis, treatment or referral or

2) is regulated or assisted by the federal government (42 U.S.C. § 290dd-2; 42 C.F.R. § 2.11-2.12; FAQ2).

42 C.F.R., 2 does not apply to state mandated child-abuse-and neglect reporting (42 C.F.R. § 2.12(c)(6)); when cause of death (42 C.F.R. § 2.15(b)) is being reported; or with the existence of a valid court order.

Determining when 42.C.F.R., 2 is applicable and how to legally access information about substance abuse treatment requires practitioners to work through a series of questions.

Generally speaking, “Part 2 sets a written consent standard for the disclosure of information contained in virtually all patient drug and alcohol health records maintained by federally funded programs” (Excerpted from Thorpe and Rosenbaum, Understanding the Interaction between EPSDT and Federal Health Information and Privacy and Confidentiality Laws, Sept 2013, p 16.)

Massachusetts law requires state licensed programs to follow 42 C.F.R. Part 2; see 105 C.M.R. 164.084, concerning client-specific information.
5. Protection of Pupil Rights Amendment (PPRA)

PPRA provides children and their families with certain privacy protections by requiring schools to notify parents in advance and to obtain written parental consent before any minor student is required to participate in any Educational Department survey that reveals certain information, including information regarding political affiliation, mental and psychological problems, sexual behavior and attitudes, certain behaviors, relationships, income and religion.

For More Information

The PPRA is available at 20 U.S.C. § 1232h; 34 CFR Part 98.
U.S. Department of Education contains a summary of PPRA:
Protection of Pupil Rights Amendment (PPRA)

Massachusetts Laws

6. Massachusetts General Law Chapter 112

Chapter 112 of the Massachusetts General Laws governs the registration of certain professionals, and contains several sections that address the issue of consent to treatment and release of information. These sections, which can be found by visiting the General Court of The Commonwealth of Massachusetts website, are:

Consent to Treatment

- Drug dependent minors consent to treatment: M.G.L. chapter 112, section 12E
  A minor, age 12 or over, who is diagnosed with drug dependency by two or more physicians may give consent to medical care related to this diagnosis, the consent of a parent or guardian is not required, and will not be liable for payment for the services. (This does not apply to methadone maintenance therapy.)
• Consent to abortion; form; persons less than 18 years of age: **M.G.L. chapter 112, section 12S**

No physician may perform an abortion without written informed consent using a form from the commissioner written in a manner designed for easy understanding by laypersons. If a pregnant woman is under 18 and unmarried, a physician cannot perform an abortion without parental or guardian consent.

The consent form is confidential and shall not be released to anyone without the consent of the woman or proper judicial authority EXCEPT that it may be released without these permissions to the woman herself, the operating physician, or the parents in cases requiring consent (i.e., if the woman is under the age of 18 and has not married). In the event that a woman under age 18 and not married does not receive parental consent (either because they are unable or unwilling to provide it, or because she does not request it) and she petitions in court for authorization of the abortion, these court proceedings will be confidential. A record of the proceedings will be maintained including the evidence and judge’s findings.

**Communications**

• Confidential Communications: Psychologists and clients: **M.G.L. chapter 112, section 129A**

Communications between licensed psychologists and the individuals with whom the psychologist engages in the practice of psychology are confidential except for in circumstances noted in the provisions of section 20B of chapter 233 with express written consent of the patient, or in circumstances that protect the rights and safety of others.

Circumstances that protect the rights and safety of others include, among others, if a patient is a danger to self or others, and refuses appropriate treatment. Follow the link below to the law for the complete list of exceptions to confidentiality.

If a psychologist must break confidentiality in order to collect payment from a patient, disclosure must be limited to the nature of services provided, the dates of services, the amount due for services and other relevant financial information, or to rebut assertions regarding his/her competence, or in “other situation as shall be defined in the rules and regulations of the board.”

• Privileged communications: patients and psychotherapists exceptions: **M.G.L. chapter 233, section 20B**
In any court proceeding, a patient can refuse to disclose or prevent a witness from disclosing any communications between patient and psychotherapist relative to the diagnosis or treatment of the patient’s mental or emotional condition. Chapter 233 lays out the types of communication when this privilege does not apply, such as if the patient is a threat to himself or others, and in certain child custody and adoption cases. The complete list of exceptions is in the link to this law above.

- **Confidential Communications: social Workers:** [M.G.L. chapter 112, section 135A](#)

  Communications between social workers and clients are confidential. At the start of the professional relationship, the social worker must inform the client that communication is confidential and the limitations of confidentiality. Limitations to confidentiality include when the client (or client’s guardian) provides express written consent.

- **Exceptions to Confidential Communications: Social Workers:** [M.G.L. chapter 112, section 135B](#)

  Massachusetts General Laws Chapter 112, Section 135B contains exceptions to the general rule. The privilege does not apply in all situations, such as when a social worker determines that a client needs hospital treatment, or that the client is a threat to the safety of him or herself or others. For additional information on when the privilege does not apply, see the text of the law, which can be found by following the link above.

- **Communications between allied mental health and human services professionals:** [M.G.L. chapter 112, section 172](#)

  Any communication between an allied mental health or human services professional and a client is confidential in all circumstances, with some exceptions, such as when the client reveals information about a crime or harmful act, or in some court cases.

- **Client of a mental health counselor has privilege against disclosures in court, legislative, or administrative proceedings:** [M.G.L. chapter 112 section 172A](#)

  The client of a licensed mental health counselor has the right to refuse to disclose or to prevent a witness from disclosing any communication between the client and mental health counselor related to the diagnosis or treatment of a client’s condition in a court, legislative or administrative proceeding. If a client is not able to waive the privilege, a guardian can be appointed to do so. The statute
lists certain communications where this privilege does not apply such as when a client is in need of hospitalization, or when the client is a threat to himself or others. To find a list of all limitations on this privilege, follow the link to the law above.

- Reporting treatment of victim of rape or sexual assault: M.G.L. chapter 112, section 12A 1/2
  Every physician attending, treating, or examining a victim of rape or sexual assault, or when such a case is treated in a hospital or other institution, the manager or other person in charge must report the case to the department of criminal justice and the police department in the town where the incident occurred. The report must not include any of the victim’s identifying information, including his or her name or address.

- Patient’s Access to Medical Records: M.G.L. chapter 112, section 12CC
  A patient is allowed access to their medical records within 30 days of the request, provided documentation of the reason for the request is supplied. (Sometimes, a fee may be charged for the records.) If a psychotherapist believes supplying the entire medical record would adversely affect the patient’s well-being, the clinician can make a summary of the record available to the patient instead. If the patient requests the entire record, despite the clinician’s determination of harm to the patient’s well-being, the clinician must make the entire record available to the patient’s attorney, with the consent of the patient, or to another clinician as designated by the patient.

- Protections for Information Related to Sexually transmitted diseases: M.G.L. chapter 111, section 119
  Hospital, dispensary, laboratory and morbidity reports and records pertaining to sexually transmitted diseases shall not be public records, and the contents of these records shall not be divulged, except upon proper judicial order or to a person whose official duties, in the opinion of the commissioner, entitle him to receive information contained therein.

7. Massachusetts General Laws Chapter 233 Governs Release of Information in Court Cases

- Domestic violence counselor: M.G.L. chapter 233, section 20K
  A domestic violence victim’s counselor shall not disclose information transmitted
in confidence between a victim and a counselor without the prior written consent of the victim, except in certain circumstances. For a list of these circumstances, follow the link above to the text of the law.

- Sexual assault, confidential communications with sexual assault counselor: M.G.L. chapter 233, section 20J
  A sexual assault counselor shall not disclose information transmitted in confidence by and between a victim of sexual assault and a sexual assault counselor, without the prior written consent of the victim. There are some limitations to this general rule. Follow the link above to the text of the law for the full list of limitations.

8. Massachusetts General Law Chapter 111 Governs Issues Related to Public Health

- HIV tests: M.G.L. chapter 111, section 70F
  No one can be tested for HIV without his or her consent. A facility, physician, or health care provider can’t test without first obtaining that person’s verbal informed consent. A health care professional cannot disclose the results of the test to anyone without the subject’s written consent or disclose the nature of the test without consent. The HIV test written consent must be distinguished from consents for the release of any other medical information.

- Confidentiality of Genetic Testing and Reports: M.G.L. chapter 111, section 70G
  No facility and no physician or health care provider shall test for genetic information without written consent. The results of the test can not be released without written consent, except in certain situations, which can be found by following the link above to the law.

9. Massachusetts General Laws chapter 123 Governs Issues Related to Mental Health

- Obligation of mental health professionals to report information about a potentially dangerous patient: M.G.L. chapter 123, section 36B
  A licensed mental health professional is NOT required to take reasonable precautions to warn or in any way protect a potential victim(s) of his/her patient, and NO cause of action is imposed against a licensed mental health professional for failure to warn or protect a potential victim(s) of his/her patient except in
certain situations, which are listed in the law, which can be found by following the link above.

10. Mass General Law 93H Requires Regulations to Protect Any MA Resident’s Personal Information

M.G.L. Chapter 93H

Massachusetts Regulations

The following is a sample of regulations governing entities in the state. Regulations in Massachusetts are found in the Code of Massachusetts Regulations (C.M.R.) and can be accessed at www.lawlib.state.ma.us

11. Department of Public Health

Protections for Information Related to Substance abuse: 105 C.M.R. sections § § 164.083-164.085

This regulation requires licensed substance abuse treatment programs to maintain thorough, up-to-date records for each patient in a confidential and secure manner. It gives clients (or someone designated in writing by the client) the right to review their records.

This regulation also requires substance abuse treatment centers to have written policies about controlling access to certain information in records, to train staff about confidentiality requirements as part of their orientation and to inform clients in writing during client orientation about these policies.

12. Department of Elementary and Secondary Education Regulations

Student Records: 603 C.M.R. 23.00

Both schools and School Based Health Centers must provide services in a manner that ensures the privacy of students and their families. These regulations note that authorized school personnel are allowed access to the student records of students when such access is required in the performance of official duties, without obtaining consent of the eligible student or parent/guardian. It is not permissible, however, to give a third party access to any information from a student record without the specific, informed, written consent of the student or parent/guardian.
For More Information

See Chapter 2 of this Guide for additional information about regulations governing confidentiality of health records and communications.

A summary of Massachusetts regulations on school records can be found at Children’s Law Center of Massachusetts, Student Records, website.

13. Department of Mental Health

Regulations that govern licensing and operations of mental health facilities provide guidance on confidentiality of records and inspection by a Department of Mental Health client and can be found on their website: Department of Mental Health.

104 C.M.R.§ 27.17(7) requires each facility to ensure confidentiality, integrity, and availability of individual records; except as provided by that section. All records relating to any persons admitted or treated by the facility shall be private and not open to public inspection.

104 C.M.R.§ 27.17(8) permits a licensed health care professional to deny patient access to records in certain circumstances, which are subject to appeal; a client who is 16 or 17 years old who admitted him or herself may inspect admittance records without consent of authorized representative; records of minor under age 18 who consented to emergency medical or dental care shall not be released except upon written consent of patient or a proper judicial order.

104 C.M.R.§ 27.17(9) sets out rules for inspection of records by others who are not the patient, including health care providers and facilities in a medical emergency.

Regarding mature minors consenting to treatment:

Where, by operation of law pursuant to M.G.L. c. 112, §§ 12E or 12F, a minor is an emancipated minor entitled to consent to drug or medical or dental treatment and is competent to do so, he or she shall be entitled to consent in the same manner as an adult. Further, a facility or program may determine, pursuant to applicable Massachusetts law, that a minor is a mature minor and is therefore able to provide consent to treatment and may decide, in certain circumstances, not to notify the parents. Such determinations should be made by facilities and programs in consultation with their legal counsel.
14. Standards for the Protection of Personal Information of Residents of MA

This regulation sets minimum standards in connection with protecting personal information of MA residents contained in paper or electronic records.

201 C.M.R. 17.00

Other Information

15. Mature Minor Doctrine

There is no uniform rule that gives minors under 18 mature minor rights. As a general rule, minors (under 18) are not legally able to consent to their own mental health treatment and medical care.

In the 1977 case Baird v. Bellotti, the Massachusetts Supreme Judicial Court adopted the “mature minor” doctrine, which, when applied to mental health treatment, holds that a minor determined by the therapist to be capable of understanding the nature and consequences of the treatment to be provided may be deemed “mature,” and thereby capable of giving consent. While a [provider] may determine that a child is a mature minor, that determination may not constrain the [provider] from notifying the client’s parent(s) if the therapist and the minor client establish those ground rules through written informed consent. Informed consent statements should always be in writing and should state the circumstances, if any, in which the [provider] will disclose information to parents.

Visit the Posternak Blankstein & Lund LLP website to for answers to Commonly Asked Questions About the Treatment of Minors (2012).

16. Board of Registration of Allied Mental Health and Human Services Professionals: Policy on Distance, Online, and Other Electronic-Assisted Counseling: Policy No. 07-03

This policy guideline was voted into effect on November 16, 2007 by the Board of Registration of Allied Mental Health and Human Services Professionals, and, like all guidelines, does not have the full effect of law. The guideline was developed in response to the increase in therapy and counseling services provided through electronic means in order to standardize care delivery through these electronic resources.
The guideline stipulates that all patient services rendered at a distance fall within the policies and regulations of the Board mentioned above, the delivery of services is considered to occur where the client is located and where the clinician is located, therefore if the patient is within MA even if the clinician is not, such services still fall under the jurisdiction of the Board.

Clinicians are expected to comply with all ethical practice guidelines as they apply to face-to-face counseling, to comply with professional association guidelines, and to have up-to-date training. Confidentiality and disclosure policies and practices are included in this policy guideline.

**For More Information**

Access the guideline on The Official Website of the Office of Consumer Affairs & Business Regulation (OCABR):

- [Policy on Distance, Online, and Other Electronic-Assisted Counseling](#)
- [The American Counseling Association Code of Ethics](#)
- U.S. Health and Human Services website, Substance Abuse and Mental Health Services Administration: [Considerations for the Provision of E-Therapy](#)

### 17. Board of Registration of Psychologists Advisory Regarding Practicing with Children and Families in MA Where Parents May Be Separated, Divorced, Or Never Married

The guideline was adopted on July 20, 2012 by the Board of Registration of Psychologists and can be found on the Board’s website [Practicing with children and families in Massachusetts where parents may be separate, divorced, or never married](#).

Under this guideline, clinicians must:

- understand the custodial rights of parents to minors whose parents are separated, divorced, or never married,
- not break confidentiality of the minor even if the parents ask them to – but only under a court order or through signed consent of the minor,
- refrain from initiating therapy with a minor without consent from both parents in the absence of protective issues or mitigating circumstances,
• understand that sole legal custody is rarely awarded in MA except in circumstances of the death of a parent, protective issues, or unmarried parents and in these circumstances, the clinician should inquire to familial circumstances before deciding whether to reach out to the non-custodial parent for consent or involvement in treatment, and

• the same clinician should not perform both psychotherapy and child custody evaluation on the same minor.

Informed consent from both parents prior to initiating child treatment that guarantees confidentiality from the parents should be obtained.

In general, working with minors with divorced, separated, or never married parents requires experience and expertise and thus clinicians should seek advice and consultation from other practitioners when needed.
Appendix B: Forms and Policies

Snapshots of a Child
1. Portable Medical Summary
2. Getting to Know My Child

Release of Information Forms
3. Massachusetts Department of Public Health Release of Information
4. Massachusetts Behavioral Health Partnership Release of Information
5. Massachusetts Department of Mental Health Two-Way Release of Information
6. HIPAA/FERPA Exchange of Information

Referral and Feedback Forms
7. Early Childhood Developmental Interagency Referral Communication Form
8. School Re-entry Form After Hospitalization

Policies
9. Boston Public Schools Student Health Policy
10. Got Transition Policy
11. Holyoke Pediatric Associates Transition Policy

Checklists
12. Health Care Transition Checklist
1. Portable Medical Summary

Source: the Center for Medical Home Improvement, Used with permission from Got Transition, the National Health Care Transition Center which is supported by a cooperative agreement U39MC18176 HRSA/ US MCHB.

This Portable Medical Summary includes space for recording information about a child/youth, along with identification of specialty providers, schools, community-based providers and their contact information.
<table>
<thead>
<tr>
<th>Practice Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date Completed</td>
</tr>
<tr>
<td>Child’s Name</td>
</tr>
<tr>
<td>DOB</td>
</tr>
<tr>
<td>Parent (Caregiver)</td>
</tr>
<tr>
<td>Address</td>
</tr>
<tr>
<td>Phone # (home)</td>
</tr>
<tr>
<td>E-Mail</td>
</tr>
<tr>
<td>Emergency Contact</td>
</tr>
<tr>
<td>Health Insurance/Plan</td>
</tr>
</tbody>
</table>

Diagnose(s): Primary: Secondary: Secondary:

Emergency Plan Yes □ Not Applicable □

Allergies
<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MEDICATIONS:**

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DOSE</th>
<th>FREQUENCY</th>
<th>MEDICATION</th>
<th>DOSE</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**SPECIALISTS:**

<table>
<thead>
<tr>
<th>PROVIDER</th>
<th>HOSPITAL</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Vital Sign (baselines): Ht Wt Other

Problem List and recommended actions (check all that apply, please explain in space below):

<table>
<thead>
<tr>
<th>Problem</th>
<th>Recommended Action</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Behavioral</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Feed &amp; Swallowing</td>
</tr>
<tr>
<td></td>
<td>Hearing/Vision</td>
</tr>
<tr>
<td></td>
<td>Learning</td>
</tr>
<tr>
<td></td>
<td>Orthopedic/Musculoskeletal</td>
</tr>
<tr>
<td></td>
<td>Physical Anomalies</td>
</tr>
<tr>
<td></td>
<td>Sensory</td>
</tr>
<tr>
<td></td>
<td>Stamina/Fatigue</td>
</tr>
<tr>
<td></td>
<td>Respiratory</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

TO BE AVOIDED:
- □ Medical Procedures:
Appendix B: Forms and Policies

### Prior Surgeries/Procedures

<table>
<thead>
<tr>
<th>#</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td></td>
</tr>
<tr>
<td>#2</td>
<td></td>
</tr>
<tr>
<td>#3</td>
<td></td>
</tr>
</tbody>
</table>

### Most Recent Labs/Diagnostics (As Appropriate)

<table>
<thead>
<tr>
<th>Test</th>
<th>Date of Procedure</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>LABWORK (Specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRUG LEVELS (Specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EEG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EKG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>X-Ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C-Spine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI/CT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Equipment/Appliances/Assistive Technology

<table>
<thead>
<tr>
<th>Item</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrostomy</td>
<td></td>
</tr>
<tr>
<td>Adaptive Seating</td>
<td></td>
</tr>
<tr>
<td>Wheelchair</td>
<td></td>
</tr>
<tr>
<td>Tracheostomy</td>
<td></td>
</tr>
<tr>
<td>Communication Device</td>
<td></td>
</tr>
<tr>
<td>Orthotics</td>
<td></td>
</tr>
<tr>
<td>Suction Monitors</td>
<td></td>
</tr>
<tr>
<td>Crutches</td>
<td></td>
</tr>
<tr>
<td>Nebulizer</td>
<td></td>
</tr>
<tr>
<td>Apnea</td>
<td></td>
</tr>
<tr>
<td>O2</td>
<td></td>
</tr>
<tr>
<td>Walker</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td></td>
</tr>
<tr>
<td>Glucose</td>
<td></td>
</tr>
</tbody>
</table>

### School/Community Information

<table>
<thead>
<tr>
<th>Agency/School/Child Care</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

### Family Information

- SPECIAL CIRCUMSTANCES/COMMENT/FAMILY/YOUTH WANTS US TO KNOW

Parent/Caregiver Signature: ___________________________ Date: __________

Primary Care Provider Signature: ________________________ Print Name: ____________________________ Contact Info: ____________________________ Date: __________

Care Coordinator Signature: ____________________________ Print Name: ____________________________ Contact Info: ____________________________ Date: __________
2. Getting to Know My Child

Source: a parent

This form can be used by families to create a ‘picture’ of the child and use it for sharing information with their child’s providers and/or school, to help these providers better understand the child.
The information on this page is written to help you work with and enjoy our child. Thank you for taking the time to read this. It can make all the difference for him/her.
3. Massachusetts Department of Public Health Release of Information

Source: the Massachusetts Department of Public Health

This form includes space for youth and families to indicate a time limit on the permission, the information to be shared, by whom and with whom.
Appendix B: Forms and Policies

Massachusetts Department of Public Health
Authorization for Release of Information
Permission to Share Information

If you want the __________________________ to share information about you with another person or organization, please make sure that you fill out all of the sections below (Sections I-VI). This will tell us what information you want us to share and who to share it with. If you leave any sections blank, with the exception of Section II (B), your permission will not be valid, and we will not be able to share your information with the person(s) or organization you listed on this form.

SECTION I
I, _______________________________________, give my permission for ___________________________ (Fill in name of person or organization) to share the information about me that I list in Section II with the person(s) or organization that I list in Section V.

SECTION II
A. Health and Personal Information
Please describe the information you want the ___________________________ to share about you. (Fill in name of person or organization)
Please include any dates and details you want to share.

B. Permission about Specific Health Information. Only if you choose to share any of the following information, please write your initials on the line:
   I specifically give permission, as required by M.G.L. c. 111, § 70F, to share information in my record about HIV antibody and antigen testing, and HIV/AIDS diagnosis or HIV/AIDS treatment.
   I specifically give permission, as required by M.G.L. c. 111, § 70G, to share information in my record about my genetic information.
   I specifically give permission to share information in my record about alcohol or drug treatment. If this information is shared, I understand that a specific notice required by 42 CFR, Part 2 shall be included prohibiting the redisclosure of this confidential information.

SECTION III – Reason for Sharing this Information
Please describe the reason(s) for sharing this information. If you do not want to list reasons, you may simply write: “at my request,” if you are initiating the request.

SECTION IV – Who May Share This Information
I give permission to the person or organization listed below to share the information I listed in Section II:

Name
Organization
Address

HIPAA-compliant Authorization 908 Form 5-A
Massachusetts Department of Public Health
Authorization for Release of Information

SECTION V – Who May Receive My Information
The person or organization listed in Section IV may share the information I listed in Section II with this person(s) or organization:

__________________________________________________________
Name

__________________________________________________________
Organization

__________________________________________________________
Address

I understand that the person(s) or organization listed in this section may not be covered by federal or state privacy laws, and that they may be able to further share the information that is given to them.

SECTION VI – How Long This Permission Lasts
This permission to share my information is good until ___________________________. Indicate date or event

If I do not list a date or event, this permission will last for one year from the date it is signed.

• I understand that I can change my mind and cancel this permission at any time. To do this, I need to write a letter to ________, and send it or bring it to the place where I am now giving
  (Fill in name of person or organization) this permission (or fill in specific location) If the information has already been given out by, I understand that it is too late for me to change my mind and cancel the permission.

• I understand that I do not have to give permission to share my information with the person(s) or organization I listed in Section V.

• I understand that if I choose not to give this permission or if I cancel my permission, I will still be able to receive any treatment or benefits that I am entitled to, as long as this information is not needed to determine if I am eligible for services or to pay for the services that I receive.

SECTION V – Signature
Please sign and date this form, and print your name.

__________________________________________________________
Your Signature

__________________________________________________________
Date

__________________________________________________________
Print Your Name

If this form is being filled out by someone who has the legal authority to act for you (such as the parent of a minor child, a court appointed guardian or executor, a custodial parent, or a health care agent), please:

Print the name of the person filling out this form: _______________________________________

Signature of the person filling out this form: ____________________________________________

Describe how this person has legal authority for this individual: ____________________________
4. Massachusetts Behavioral Health Partnership Release of Information

Combined MCE Behavioral Health Provider/Primary Care Provider Communication Form

Source: the Massachusetts Behavioral Health Partnership website, MassHealth, and its contracted health plans.

This form is designed to support communication between behavioral health care and primary care providers and includes space to enter information about a child.
Combined MCE Behavioral Health Provider/Primary Care Provider Communication Form

<table>
<thead>
<tr>
<th>Health Plan:</th>
<th>Boston Medical Center HealthNet Plan</th>
<th>Network Health</th>
<th>Fallon Community Health Plan</th>
<th>Neighborhood Health Plan</th>
<th>PCC Plan</th>
<th>HNE</th>
</tr>
</thead>
</table>

The member below is currently receiving services and has consented to share the following information between his/her PCP and BH provider.

In an effort to increase communication and promote care coordination between providers, we ask that you review and/or complete the following health information:

Member Name: ___________________ DOB: ___________________ Member ID#: ___________________

A signed copy of the release of information (ROI) must be attached to this form. Indicate date of expiration of ROI: ___________________

### Section A: (completed by BH Provider)

1. The patient is being treated for the following behavioral health problem(s) and/or diagnoses: (list all)

2. The patient is taking the following medication(s): (list all prescribed and OTC medications, with dosage and frequency as applicable)

3. The patient has the following substance abuse problem(s) (if applicable):

4. Please describe any special concerns (i.e., include abnormal lab results):

Behavioral Health Clinician: ___________________
Behavioral Health Clinician Signature: ___________________
Provider Name/Site Name: ___________________
Address: ___________________

Phone: ___________________
Fax: ___________________
Date this form completed: ___________________

### Section B: (completed by Primary Care Provider)

1. The patient is being treated for the following medical problem(s) and/or diagnoses: (list all)

2. The patient is taking the following medication(s): (list all prescribed and OTC medications, with dosage and frequency as applicable)

3. The patient has the following BH (MH/SA) problem(s) (if applicable):

4. Please describe any special concerns (i.e., include abnormal lab results):

Primary Care Provider: ___________________
Primary Care Provider Signature: ___________________
Provider Name/Site Name: ___________________
Address: ___________________

Phone: ___________________
Fax: ___________________
Date this form completed: ___________________

To make a referral to Care Management, please call the members’ plan at:

Boston Medical Center HealthNet Plan: (888) 444-5155 • Network Health: (888) 267-9986 • Fallon Community Health Plan: (888) 421-8961 • Neighborhood Health Plan: (800) 414-2620 • Primary Care Clinician Plan: (817) 790-5833 • Health New England: (817) 790-5833

(Updated 10/15/2019)
5. Massachusetts Department of Mental Health Two-Way Release of Information

Source: the Massachusetts Department of Mental Health

This form supports the exchange of information between the Department of Mental Health and other parties.
Appendix B: Forms and Policies

COMMONWEALTH OF MASSACHUSETTS
DEPARTMENT OF MENTAL HEALTH

Authorization for Release of Information
Two-Way

Name: Other Name(s):
Address: Phone:
Social Security #: Date of Birth:

I authorize the Department of Mental Health (DMH) to receive and release information from or to the person, agency or facility named below, either verbally or in writing, as indicated in this authorization.

Name: Attention: Phone:
Street: City/Town: State:
Zip:

DMH Contact Information:
Name: Phone:
Address:

The person filling out this form must provide details as to date(s) of requested information. Please note that a request for release of psychotherapy notes cannot be combined with any other type of request. Specify information to be released e.g., entire record, admission(s) documentation, discharge summary(s), transfer summary(s), evaluations, assessments and tests, consultation(s) including names of consultant(s), treatment plan(s), ISP(s) & IAP(s), physical exam & lab reports, progress note(s):

[Blank lines for details]

Purpose for the authorization:
☐ The subject of the information or Personal Representative initiated the authorization (specific purpose not required)
☐ Coordinate care ☐ Facilitate billing
☐ Referral ☐ Obtain insurance, financial or other benefits
☐ Other purpose (please specify)

A copy of this authorization shall be considered as valid as the original.

Page 1 of 2
HIPAA-P-4 (4/7/11)
COMMONWEALTH OF MASSACHUSETTS
DEPARTMENT OF MENTAL HEALTH

Authorization for Release of Information
Two-Way (continued)

Name of person/facility/agency other than DMH to receive or release information: ________________________________

I understand that I have a right to revoke this authorization at any time. If I revoke this authorization, I must do so in writing and present it to DMH at DMH address identified on page one. I understand that the revocation will not apply to information that has already been released pursuant to this authorization. I understand that the revocation will not apply to my insurance company when the law provides my insurer with the right to contest a claim under my policy. This authorization will expire (specify a date, time period or an event). __________________________ or, if nothing is specified, it will expire when I am no longer receiving services from DMH. I understand that once the above information is disclosed to a person, facility or agency outside DMH, the recipient may redisclose it and the information may not be protected by federal or state privacy laws or regulations. I understand that authorizing the use or disclosure of the information identified above is voluntary. I need not sign this form to receive treatment or services from DMH and/or the other named person, facility or agency. However, lack of ability to share or obtain information may prevent DMH, and/or the other named person, facility or agency, from providing appropriate and necessary care.

X
Your signature or Personal Representative’s signature

Print name of signer

THE FOLLOWING INFORMATION IS NEEDED IF SIGNED BY A PERSONAL REPRESENTATIVE

Type of authority (e.g., court appointed, custodial parent) ________________________________

Specially Authorized Releases of Information (please initial all that apply)

X To the extent that my medical record contains information concerning alcohol or drug treatment that is protected by Federal Regulation 42 CFR, Part 2, I specifically authorize release of such information.

X To the extent that my medical record contains information concerning HIV antibody and antigen testing that is protected by MSL c.111 §70F, an HIV/AIDS diagnosis or treatment, I specifically authorize disclosure of such information.

INSTRUCTIONS:
1. This form must be completed in full to be considered valid.
2. Distribution of copies: original to appropriate DMH record; copy to Individual or Personal Representative; copy to person/facility/agency making request.

DMH Authorization for Release of Information - Two Way
HIPPA-F-4 (4/7/11)
6. HIPAA/FERPA Exchange of Information

Source: Boston Public Schools

This form supports the exchange of information between schools in MA and health care providers. It has space for the school and providers to insert information about the child and the family or youth to indicate the timeframe for which the permission is valid.
Appendix B: Forms and Policies

<<District Name>>

HIPAA/FERPA Compliant Authorization for the Exchange of Educational And Health Information

Patient/Student Name: ___________________________ Date of Birth: _____________

School: _______________________________________

Phone: ___________________________ Fax: ___________________________

School Nurse: ___________________________ Health Care Provider: ___________________________

The purpose of this form is to facilitate communication between a school nurse and the child’s health care provider, for the purposes of optimizing the student’s learning experience. The school nurse may share information provided in this medical report with appropriate members of the educational team for use in meeting the student’s health and educational needs. This will be done on a “need to know” basis, in a confidential manner and may also include communication between health provider and school nurse to facilitate this process. Likewise, the medical provider may share information with the hospital or clinical team. Only those areas listed below will be shared.

<table>
<thead>
<tr>
<th>Health information from Health Care Provider to School (May attach additional management plans and ICHP)</th>
<th>Educational Information from the school to the Health Care Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Issue:</td>
<td>Issue</td>
</tr>
<tr>
<td>Information to be shared:</td>
<td>Information to be shared:</td>
</tr>
</tbody>
</table>

Authorization

This authorization is valid for one calendar year. It will expire on __________ I understand that I may revoke this authorization at any time by submitting written notice of the withdrawal of my consent. I recognize that health records, once received by the school district, may not be protected by the HIPAA Privacy Rule, but will become education records protected by the Family Educational Rights and Privacy Act. By agreeing to allow communication between the health care provider and designated school health I also understand that if I refuse to sign, such refusal will not interfere with my child’s ability to obtain health care.

_________________________________________    ____________
Parent Signature                      Date

_________________________________________    ____________
Student Signature*                    Date

*If a minor student is authorized to consent to health care without parental consent under federal or state law, only the student shall sign this authorization form. In Massachusetts, a competent minor, depending on age, can consent to outpatient mental health care, alcohol and drug abuse treatment, testing for HIV/AIDS, and reproductive health care services.
7. Early Childhood Developmental Interagency Referral Communication Form

Source: Olmsted County Communities Collaborating for Healthy Development team, Minnesota

This form can be adapted for use by Primary Care Providers to make referrals to Early Intervention (EI) services. It includes space for the EI provider to communicate back to the Primary Care Provider.
Early Childhood Developmental Interagency Referral Communication Form

The information contained in this form is privileged and confidential information. If you are neither the intended recipient nor the employee or agent responsible for delivering this information to the intended recipient, you are hereby notified that any disclosure, copying, distribution or taking of any action in reliance on the content of this telecopied information is strictly prohibited. When sending this form, always attach the patient’s current consent form.

Date: 

TO: 
(name, title) 
(phone) 
(fax) 
(address) 

FROM: 
(name, title) 
(phone) 
(fax) 
(address) 

CHILD INFORMATION

Child ID Number: 
Child’s Name: 
DOB: 
Gender: M F 
Parent/Legal Guardian: 
Relationship: 

Primary Language: English Spanish Hmong Somali Other: 
Interpreter Needed: Yes No 

Home Address: 
Phone: 
Insurance: 

Known Pertinent Medical History: 

REASON FOR REFERRAL (please check all that apply)

☐ Developmental Screening Tool Concern
☐ Mental Health Screening Tool Concern
☐ Medical Health/Growth Concern
☐ Suspected developmental delay or concern
☐ Other Comments:

Identified automatic qualification condition for early childhood services? 

No Yes (if yes, list)

OTHER REFERRALS

Audiology: 
Social Worker: 
Home Care: 
Medical Specialists: 
Public Health Nursing: 
Mental Health: 
Private OT/PT/SLP: 
Help Me Grow/direct website: 

WHEN RETURNING THIS FORM, PLEASE INDICATE ATTACHED INFORMATION

☐ Consent form
☐ Developmental Screening, Assessment Information
☐ Mental Health Screening Assessment Information
☐ Individualized Education Plan/Individualized Family Service Plan
☐ Medical Reports, Diagnoses, Prescriptions
☐ Evaluation results/observations/progres report
☐ Summary of presenting problems

RETURN COMMUNICATION (expected within 45 days B-3, 90 days 3-5)

☐ Evaluation in process
☐ Parent declined
☐ No response from parent
☐ Client not seen within 60 days

Result of the assessment: Qualification: Yes No 

Date services started: 

If no, ongoing monitoring? 
Yes No; Follow-up plan

If yes, describe plan of action/services provided (i.e. frequency, duration, location, and type of service):

Other relevant details/comments:

Recommendations to referral source:

RETURN TO:

☐ Olmsted County Public Health
☐ Help Me Grow
☐ Early Childhood Screening (Fax: 507-328-4015)
☐ Mayo Clinic
☐ Other Medical Provider

Head Start/School Readiness
Olmsted Medical Center

Appendix B: Forms and Policies
8. School Re-Entry After Hospitalization Form

Source: Massachusetts Department of Public Health School Unit and Children’s Behavioral Health Initiative

This form can be used for students who have been hospitalized for behavioral/mental health issues in order to facilitate a smooth and easy transition back to school.
PUBLIC SCHOOLS

BEHAVIORAL HEALTH

Re-Entry to School Referral

Student Name: ___________________________ DOB: ______________

School: __________________________________ Grade: ____________

Anticipated Date of Return to School: __________________________________

Primary contact person at school: _________________________________

Secondary contact person: _________________________________

Physician/therapist: _________________________________________

Phone: ___________________________ Email: _______________________

_________________________________________________________________

THIS SECTION IS ONLY TO BE FILLED OUT BY A PHYSICIAN/THERAPIST

Functional Diagnosis: __________________________________________

DSM Diagnosis (optional): _______________________________________

Behavioral Health Concerns:

______________________________________________________________

______________________________________________________________

Maladaptive defenses: __________________________________________

______________________________________________________________

______________________________________________________________

Triggers: ______________________________________________________

______________________________________________________________

Coping Strategies/ Interventions: _________________________________

______________________________________________________________

______________________________________________________________

Relaxation/de-escalation techniques preferred /interventions: __________

______________________________________________________________

Medication(s): ________________________________________________

Date(s) Started: ______________________________________________

Side Effects: _________________________________________________

6/4/2014

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Student/Family reply to questions about absence:

________________________________________________________________________

________________________________________________________________________

Considerations that may affect academic performance:

________________________________________________________________________

________________________________________________________________________

Physician/therapist signature ___________________________ Date ____________

I hereby authorize ___________________________ of ___________________________

Name ___________________________ Address/Organization

and ___________________________ of ___________________________

Name ___________________________ School Affiliation

to release information concerning ___________________________ to one another.

Name of Student

I also hereby release both parties from all liability and all claims pertaining to the
disclosure of this information.

Parent/Guardian Name (Print): ___________________________

Parent/Guardian Signature: ___________________________

Phone: ___________________________ Email: ___________________________

Public Schools person receiving this form: ___________________________

Signature

Forwarded to: ___________________________ Date: ___________________________

Name/Position
9. Boston Public Schools Student Health Policy

Source: The Superintendent of Boston Public Schools

This is the 2011/12 policy on student health records, providing guidance to schools on rules that apply to confidentiality of information in the student record.
STUDENT HEALTH INFORMATION

State and Federal laws and regulations dealing with the confidentiality of student record information recognize that student health information is treated differently from other student record information. It should be noted that the Health Insurance Portability and Accountability Act, also known as HIPAA, does not apply to student records, with some exceptions not germane to this policy. See 85 Fed. Reg. 82805 (2000). School health personnel may have access to student health records, when such access is required in the performance of their official duties. 803 Code Mass. Regs. §23.07 (4)(h). Of course, a parent/guardian or in some circumstances the student himself or herself may consent to the release of student health record information to school personnel generally. In the absence of such informed written consent, however, the following standards should apply to a determination of which school officials may access what parts of a student’s health record. In the first instance, such determinations should be made by the building administrator, in consultation with the school-based nurse. If a disagreement arises, such concerns should be brought to the attention of the Director of Medical Services, Student Support Services, for resolution.

The following guidelines should be used:

1. **Routine medical information.** Such student health information should be disseminated only as is appropriate to meet the regular and effective educational mission of the school. Such information may include information contained in an IEP or 504 Plan, previously scheduled medical appointments, health-related incidents that may require or necessitate further reporting, or dispensation of medications. In all events, only the minimum necessary health record information should be disclosed. Thus, the type of medications dispensed would, absent more, not be disclosed in the above example. The fact that a medical appointment, necessitating early dismissal, is with a psychiatrist, would also not normally be disclosed as a matter of routine medical information.

   Routine medical information is information that is appropriate for certain staff to know in order to maximize the safety for children. For example, a child with diabetes needs to have teachers who are knowledgeable about the illness, in order for the child to have a safe learning environment. Low blood sugar can also affect the child’s ability to concentrate. In this circumstance it would be appropriate to notify all of the child’s teachers, individually. Health information should never be circulated by an all-staff memo.

2. **Medical information of limited dissemination.** Such student health information that is of a confidential nature and yet is of little educational benefit in the school. This is specific information that the Student Support Team needs to know to provide accommodations. When possible, all diagnoses, especially those related to mental health, should be expressed as a functional diagnosis. For example, it should be enough for the team to know that a child who is depressed is getting counseling. The details of the diagnosis or the causes of the depression are not relevant to the team’s provision of accommodations. The nurse provides the connection with the provider to interpret the medical information or when clarification is required.

3. **Highly sensitive information.** Such student health information of a highly sensitive nature that has no bearing on educational achievement and is of no educational use or consequence and in which a high expectation of privacy exists for students and/or parents or guardians. Such information may include: suicide attempts, treatment for drug or alcohol abuse, mental health diagnoses, family planning information, paternity/maternity tests or information, abortions, or HIV infection. This information is of two types: (1) no accommodations or safety issues and (2) highly sensitive
information. Medical diagnoses that have no relevance to a student’s performance do not need to be shared. For example, a child in therapy who is depressed but not suicidal and who is performing well in school, does not need to have this information shared with the school community. There are also highly sensitive medical situations that are protected by state regulations. These include HIV and a minor’s right to seek medical care for pregnancy, sexually transmitted diseases and substance abuse, without their parents’ consent. Any inclusion of this information in the educational record is a violation of the adolescent’s right to privacy. With HIV, the student/family can choose to disclose and can limit the individuals to disclose to. In some circumstances, such information is of such a private nature that even dissemination to a parent or guardian is prohibited. Questions in this regard should be directed to the Office of Legal Advisor. Such highly sensitive health information should, whenever possible, be segregated from the rest of a student’s health information to reduce the chance of inadvertent disclosure.

For more information about this circular, contact:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Alissa Ocasio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department:</td>
<td>Office of Legal Advisor</td>
</tr>
<tr>
<td>Mailing Address:</td>
<td>26 Court Street, Boston, MA 02108</td>
</tr>
<tr>
<td>Phone:</td>
<td>617-635-9320</td>
</tr>
<tr>
<td>Fax:</td>
<td>617-635-9327</td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:ocasio@boston.k12.ma.us">ocasio@boston.k12.ma.us</a></td>
</tr>
</tbody>
</table>

Carol R. Johnson, Superintendent
10. Got Transition Policy

Source: the National Health Care Transition Center, a program of the Center for Medical Home Improvement. Used with permission from Got Transition, the National Health Care Transition Center which is supported by a cooperative agreement U39MC18176  HRSA/ US MCHB.

This policy document provides ideas and suggestions for primary care providers for creating and implementing a policy for transitioning youth from pediatric to adult primary care.
Sample Transition Policy

Six Core Elements of Health Care Transition 2.0

[Pediatric Practice Name] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.
11. Holyoke Pediatric Associates Transition Policy

Source: Holyoke Pediatric Associates website

This document is an example of this practice’s stated policy on transitioning youth from pediatric to adult primary care.
POLICY ON TRANSITION TO ADULT HEALTH CARE

Holyoke Pediatric Associates (HPA) strives to serve as our patients’ Medical Home by partnering with patients and parents/guardians to deliver comprehensive, coordinated, family-centered care. We seek to respect both our patients’ legal rights to privacy and parents’/guardians’ concerns for the well-being of their child or young adult. We assist our patients to learn and practice the skills they will need as adults to become responsible for their own health and to manage their health care. We work with patients and families to assure a smooth transition to adult health care.

Patients 12-17 years old:
Beginning at age 12 years, at least part of a patient’s medical visit will generally be in private, and the parent/guardian will be asked to step out of the exam room. The patient or parent/guardian may ask for a nurse to be present in the exam room. Discussions of certain sensitive issues, such as sexual and mental health and substance use, will remain confidential and will not be shared with the parent/guardian unless the adolescent requests. Medical records documenting the corresponding portions of the medical exam and discussion also will be treated as confidential, to the extent required by law, and will be released to a parent/guardian or other person only with the patient’s written authorization.

For adolescent patients who have developmental disabilities or other special health needs, it may be necessary and appropriate to modify these policies to accommodate their needs. We welcome patients and parents/guardians to discuss special needs with us, so that we may plan reasonable accommodations together.

In addition, HPA will inform the parent/guardian of any life-threatening situation or behavior involving any patient younger than age 18 years, whether disclosed by the patient or becoming evident through medical examination. In this case, we will inform the patient that we will disclose or have disclosed this information to the parent/guardian.

Patients 18 years and older:
Patients 18 years and older are adults under the law.

HPA will respect these patients right to make their own health care decisions and manage their own health care, unless a court has determined that they are not able to do so and has appointed a legal guardian. Please provide us a copy of the court’s decree or equivalent documentation, if you have been appointed the legal guardian of your adult child so that we may conform to the terms of your guardianship.

HPA requires patients 18 years and older to make their own appointments at HPA, request their own referrals, and communicate about other care, billing, and insurance matters. We will gladly assist our patients of any age to understand and practice these skills. HPA cannot communicate with a parent or
other person on the patient's behalf unless s/he is the legal guardian or authorized health care agent (proxy), or the patient has provided a written release.

HPA will respect the right of patients age 18 years and older to privacy regarding their health information and records. Providers will meet with and examine these patients privately unless the patient requests that the parent or other person be present. A young adult patient may authorize a parent or other person to receive medical information or records by signing a release of information. A release form is available at www.holyokepediatrics.com (in the left margin, click “Downloadable Forms”; then click “Authorization to release medical records”) or you may ask your HPA provider or Medical Records for a copy.

Understanding your insurer’s privacy policies:
Please be aware that young adults and children, who are insured under a parent’s family policy, might receive statements from the insurer at the parent’s address. HPA has no control over insurers’ procedures and is not responsible for any resulting disclosure of health information. Please contact your insurer about any questions regarding its privacy procedures and policies.

Transitioning from pediatric to adult health care: a partnership:
HPA serves patients from birth to 22 years of age. We welcome our young adult patients to continue in our care until they are 22 years old. By that age, patients should transition to an adult primary care provider (usually a doctor, nurse practitioner, or physician assistant practicing Family Medicine or Internal Medicine), as well as adult providers for any medical specialty care the patient may receive. We encourage you to start collecting information about adult health care providers well before age 22, usually around age 18-21 years. Remember to check with your insurer or ask the adult provider which insurances are accepted.

We are available to discuss health care transition with patients and families. We are committed to partnering with you throughout the process to assure a smooth transition.

Once you select you adult provider, please remember to sign a release promptly so we may send your medical records to this provider. You may use HPA’s release form at www.holyokepediatrics.com, the adult provider’s form, or other equivalent form. Please be aware that HPA disposes of medical records according to state law. This generally means that we retain records for seven years after the last date of service or until age 18 years, whichever is longer.

These policies follow generally accepted guidelines for pediatric practices, and federal and state law, including HIPAA (the federal Health Insurance Portability and Accountability Act) and Mass. General Laws (MGL). Please refer to: MGL c. 112 §12F and §12S Minors and Treatment for Pregnancy and Prenatal Care; MGL c. 111 §117 Minors and Treatment for Sexually Transmitted Diseases and HIV/AIDS; MGL c. 123 §10 Minors and Treatment for Mental Health; and MGL c. 112 §12E Minors and Treatment for Substance Abuse. This policy is not legal advice. Please consult a lawyer if you need legal advice.
12. Health Care Transition Checklist

Source: National Health Care Transition Center, a program of the Center for Medical Home Improvement. Used with permission from Got Transition, the National Health Care Transition Center which is supported by a cooperative agreement U39MC18176 HRSA/ US MCHB.

This checklist is designed to help Primary Care Providers track and monitor the implementation of the steps to transitioning a youth from pediatric to adult primary care.
# Health Care Transition Transfer of Care Checklist (Pediatric)

<table>
<thead>
<tr>
<th>Patient Name &gt;</th>
<th>Date of Birth &gt;</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Transfer of care policy discussed with youth and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Transfer of care options discussed with youth and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Timing of transfer of primary care discussed with youth and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Option of using the family's existing adult primary care provider(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Review of the practice's list of available adult primary care providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Options and timing for transfer of specialty care discussed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Pediatric primary care practice confirms transfer with adult primary care practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o For youth with special health care needs, personal communication between pediatric and adult primary care providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Date of transfer of care determined with mutual agreement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Final youth readiness assessment completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Transfer of care package prepared or updated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o For all youth, include the following:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Cover or referral letter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Current portable medical summary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Most recent readiness assessment with action plan status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Final transition plan including</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Name and contact information for pediatric primary care provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Name and contact information for new adult primary care provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Effective date for transfer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o For youth with special health care needs, include the following:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Cover or referral letter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Current portable medical summary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Condition-specific “fact sheet”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Current HCT action plan of pending and upcoming activities needing attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Emergency care plan – what’s an emergency, what to do</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
- Most recent readiness assessment

- Relevant information, if appropriate, regarding guardianship, custodial arrangements, and powers of attorney

- Final transition plan including
  - Name and contact information for pediatric primary care provider
  - Name and contact information for new adult primary care provider
  - Effective date for transfer
  - Preferred means of interim communication and consultation between pediatric primary care team and adult primary care team identified and documented

- Transfer of care package communicated to adult primary care provider via best available means (mail, fax, email, electronic health information transfer)

- Initial visit with new adult primary care provider scheduled

- Follow-up communication with emerging adult (and family as appropriate) by pediatric primary care team regarding completion of transfer of care and level of satisfaction with result

- Follow-up communication with new adult primary care team by pediatric primary care team regarding completion of transfer of care and level of satisfaction with results; identify any future plans/needs for on-going communication or consultation
Appendix C: Resources

About Communication


About Confidentiality Laws


About Primary Care Practices
Patient Centered Medical Home. Some primary care practices are using a new way to deliver care, called the patient centered medical home. The idea is to give
complete care that is family-centered, compassionate, and culturally comfortable to all children and youth, including those with special health care needs. Visit [http://pcmh.ahrq.gov](http://pcmh.ahrq.gov) to learn more about medical homes.

### About Schools


2. To learn more about services available in schools, visit [http://www.doe.mass.edu/mtss/default.html](http://www.doe.mass.edu/mtss/default.html).

### About Schools and Behavioral Health


### For Children, Youth, and Families


2. The Center for Children with Special Needs: [Creating Care Plans for Youth](http://www.mass.gov/eohhs/gov/departments/dph/programs/family-health/directions/)


### For Primary Care Practices


3. Got Transition? The National Health Care Transition Center is a program of the Center for Medical Home Improvement. Go to [www.gottransition.org](http://www.gottransition.org) to find forms and policies on the transition to adulthood.

4. Strategies for system change in children's mental health, a chapter action kit, American Academy of Pediatrics, 20017. This toolkit includes a physician and referral form (p. 4-11, 4-12) that can be used by primary care providers to make referrals to behavioral health providers. It includes space for the reason for referral and outcome of the referral or visit from the behavioral health provider. [http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/finalcak.pdf](http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/finalcak.pdf)

5. Massachusetts Child Psychiatric Access Project (MCPAP). When a primary care practice does not have a behavioral health provider as part of their team, the primary care provider can still access consultative services from a child-focused behavioral health provider through MCPAP. MCPAP is a system of regional children's mental health consultation teams that are available to assist primary care providers with delivering some care for behavioral health needs, and, when appropriate, may reduce the number of providers that the child needs to see. Pediatric practices can register for MCPAP at [http://mcpap.com/SignUp2.asp](http://mcpap.com/SignUp2.asp).

For Schools

For Schools and Primary Care Providers
Appendix D: Creating Care Maps and Contact Lists

Draw Your Own Care Map and Make Your Own Contact List

To get ideas for who to include in your care map, take a look at the table below. When you’re ready, use the blank page after the table to draw your own care map. If you get stuck, you can always look back at the table or at the care map example shown above.
## Appendix D: Creating Care Maps and Contact Lists

### For health care needs such as

<table>
<thead>
<tr>
<th><strong>Primary care</strong></th>
<th>You may want to add names of</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Primary care providers</td>
<td></td>
</tr>
<tr>
<td>• Medical assistants</td>
<td></td>
</tr>
<tr>
<td>• Nurses</td>
<td></td>
</tr>
<tr>
<td>• Physician assistants</td>
<td></td>
</tr>
<tr>
<td>• Social workers</td>
<td></td>
</tr>
<tr>
<td>• Care coordinators</td>
<td></td>
</tr>
<tr>
<td>• Secretaries, Administrative assistants, Receptionists</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Dental care</strong></th>
<th><strong>Dentists</strong></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Behavioral health care</strong></th>
<th>You may want to add names of</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Psychiatrists</td>
<td></td>
</tr>
<tr>
<td>• Psychologists</td>
<td></td>
</tr>
<tr>
<td>• Neuropsychologists</td>
<td></td>
</tr>
<tr>
<td>• Social workers</td>
<td></td>
</tr>
<tr>
<td>• Peer supports</td>
<td></td>
</tr>
<tr>
<td>• Counselors</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Specialists</strong></th>
<th>You may want to add names of</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any specialist who sees your child regularly, such as:</td>
<td></td>
</tr>
<tr>
<td>• Cardiologists (heart doctors)</td>
<td></td>
</tr>
<tr>
<td>• Developmental specialists</td>
<td></td>
</tr>
<tr>
<td>• Physical, occupational and speech therapists</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Hospitals</strong></th>
<th>You may want to add names of</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hospitals your child uses regularly</td>
<td></td>
</tr>
<tr>
<td>• Hospital departments your child visits regularly (like hematology, endocrine, genetics, cardiology)</td>
<td></td>
</tr>
<tr>
<td>• Social workers</td>
<td></td>
</tr>
<tr>
<td>• Other staff that regularly work with your child</td>
<td></td>
</tr>
<tr>
<td><strong>Medical equipment providers</strong></td>
<td>Providers you use for medical equipment, like wheelchairs, and respiratory equipment, such as a nebulizer.</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Prescription drugs</strong></td>
<td>Pharmacies you use for your child, including mail order services.</td>
</tr>
</tbody>
</table>
| **Home health providers**    | All health providers that give care to your child in your home, school, or other non-medical settings, like at your child’s daycare provider  
- Nurses  
- Therapists  
- Home health aides  
- Personal care attendants |
| **Translation services**     | People who help you when you do not speak the same language as the person helping the child. |

### For people at school such as

| **School staff** | You may want to add names of  
- Principals  
- Teachers  
- Other school staff that help you regularly |
| **Special education staff** |  
- Special education directors  
- Special education teachers  
- Classroom aides |
| **School health providers** |  
- School nurses  
- School doctors  
- Physical, occupational and speech therapists  
- Respiratory therapists  
- Nutritionists |
| **School behavioral health providers** | • School psychologists  
• School adjustment counselors |
| **Transportation providers** | • Bus service  
• Volunteer driver |
| **For information, advocacy, and leadership support such as** | **You may want to add names of** |
| **Family and professional partnerships** | • Patient and Parent Advocacy League  
• Youth MOVE Massachusetts |
| **Organizations** | • Massachusetts Family Voices  
• Parent Teacher organizations |
| **For community needs such as** | **You may want to add names of** |
| **Recreation** | Anyone in the community that sees your child regularly, like:  
• Coaches  
• Camp counselors  
• Boys and Girls Club staff  
• YMCA and YWCA staff |
| **Community-based providers** | Non-medical providers in the community that work with your child, like Early Intervention. |
### Other supports in your community

- Neighbors
- Places of worship
- Babysitters
- Work-related supports, like career counselors, people you work with, and supervisors
- First responders, fire and police personnel

### For legal and financial needs such as

<table>
<thead>
<tr>
<th>You may want to add names of</th>
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<tbody>
<tr>
<td>Insurance</td>
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<tr>
<td>Insurance companies you use for your child, like:</td>
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<tr>
<td>• Medicaid</td>
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<tr>
<td>• Private health insurance</td>
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<tr>
<td>• Dental insurance</td>
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<td>• Vision insurance</td>
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<tr>
<th>Legal and financial help</th>
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<tbody>
<tr>
<td>Anyone that helps your family with financial or legal issues, like:</td>
</tr>
<tr>
<td>• Health insurance case managers</td>
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<td>• Financial assistance workers</td>
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<tr>
<td>• Lawyers</td>
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<tr>
<td>• State care managers</td>
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<tr>
<td>• Housing support</td>
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<tr>
<td>• Legislators</td>
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<tr>
<td>• Federal, state, and local agencies (like WIC and Food Stamps)</td>
</tr>
<tr>
<td>For support you get from</td>
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<tr>
<td>-------------------------------</td>
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<tr>
<td><strong>People close to you</strong></td>
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<tr>
<td><strong>Community groups</strong></td>
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<td><strong>Therapists</strong></td>
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<td><strong>Social media and blogs</strong></td>
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</tbody>
</table>
Draw your care map in the space below:
Create Contact List Using Your Care Map

Because care maps show all the people you may need to communicate with, they give you a great start for building a contact list. Here’s what a partly filled in contact list looks like:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Address</th>
<th>Phone</th>
<th>Fax</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Snow</td>
<td>PCP</td>
<td>123 Main St. Jamaica Plain, MA 02130</td>
<td>555-555-5555</td>
<td>444-444-4444</td>
<td><a href="mailto:Snow@doctor.com">Snow@doctor.com</a></td>
</tr>
<tr>
<td>Ellen Jones</td>
<td>Care</td>
<td>123 Main St. Jamaica Plain, MA 02130</td>
<td>555-555-5111</td>
<td>444-444-4111</td>
<td><a href="mailto:Jones@doctor.com">Jones@doctor.com</a></td>
</tr>
<tr>
<td>Dr. Frost</td>
<td>Dentist</td>
<td>123 Center St. Boston, MA 02201</td>
<td>333-333-3333</td>
<td>222-222-2222</td>
<td><a href="mailto:frost@dentist.com">frost@dentist.com</a></td>
</tr>
</tbody>
</table>
Create your own contact list. In the table below, fill in contact information for everyone on your care map.

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Address</th>
<th>Phone</th>
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