

Tips, Tools, and Resources for Children, Youth, and Families

Chapter

4

At a Glance

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?



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.

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

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



To learn more about organizing information about your child, visit the [Family Ties of Massachusetts](#) website and look into attending one of their **Let's Get Organized** workshops.

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.