Tips, Tools, and Resources for Primary Care Providers

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 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.

"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."[17]

—Kenneth R. Ginsburg, MD

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:

- 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 plans 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 me 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.

Disease Monitoring and Management

The eDMC (electronic Developmental Medicine Center) developed by Boston Children's Hospital is a web-based disease monitoring and management system. It allows parents and teachers to fill out questionnaires about a child's behavior, ADHD medication effects, and symptoms. Information is sent directly to the pediatrician in time for the child's follow-up visit. Scores are graphed over time so the pediatrician can determine whether to make any medication changes. You can read more about shadowing ADHD with web-based tools at the Boston Children's Hospital Vector blog.

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