

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



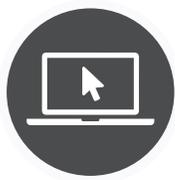
Primary Care
Providers



Behavioral Health
Providers



Schools



Web Link



Quote

Funded by the Centers for Medicare and Medicaid Services (CMS) through grant funds issued pursuant to CHIPRA section 401(d). The statements and opinions expressed in this Guide are those of the authors and not those of CMS.

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

Contents

	About This Guide	6
1	Why Share Information?	9
	Introduction	10
	Better Communication Means Better Care	10
	Supporting Good Communication	12
	Language and Culture Challenges	14
2	Sharing That Builds Trust and Honors Privacy	17
	Building Trust	18
	Common Concerns about Information Sharing	18
	What Are the Main Privacy Laws?	21
	How to Get Consent	24
	What Can Be Shared without Consent?	27
3	A Closer Look at the Child’s Network	29
	Care Maps	30
	Care Coordination	32
	A Closer Look at the Child, Youth, and Family Team	34
	A Closer Look at the Primary Care Team	39
	A Closer Look at the Behavioral Health Team	41
	A Closer Look at the School Team	43
4	Tips, Tools, and Resources for Children, Youth, and Families	47
	Tips for Building Trust	48
	Getting the Information You Need	49
	Questions to Ask Yourself Before Sharing Information	52
	Tips for Better Communication	52
	Protecting Your Child’s Privacy	55
	Supporting the Transition to Adulthood	56

5**Tips, Tools, and Resources for Primary Care Providers 57**

Tips for Building Trust	58
Getting and Sharing the Right Information	61
Questions to Ask Yourself Before Sharing Information	64
Tips for Better Communication in Your Practice	65
Protecting Privacy in Your Practice	67
Supporting the Transition to Adulthood	69

6**Tips, Tools, and Resources for Behavioral Health Providers 71**

Tips for Building Trust	72
Getting and Sharing the Right Information	74
Questions to Ask Yourself Before Sharing Information	78
Tips for Better Communication	78
Protecting Privacy	79
Supporting the Transition to Adulthood	80

7**Tips, Tools, and Resources for Schools 81**

Tips for Building Trust	82
Getting and Sharing the Right Information	84
Questions to Ask Yourself Before Sharing Information	86
Tips for Better Communication	87
Protecting Privacy	88
Supporting the Transition to Adulthood	89

Acknowledgments 90**References 92**

A**Appendix A: Laws and Regulations****95****B****Appendix B: Forms and Policies****113**

Portable Medical Summary	114
Getting to Know My Child	117
MA DPH Release of Information	119
MBHP Release of Information	122
MA DMH Two-Way Release of Information	124
HIPAA/FERPA Exchange of Information	127
Early Childhood Developmental Interagency Referral Communication Form	129
School Re-Entry after Hospitalization Form	131
Boston Public Schools Student Health Policy	134
Got Transition Policy	137
Holyoke Pediatric Associates Transition Policy	139
Health Care Transition Checklist	142

C**Appendix C: Resources****145****D****Appendix D: Creating Care Maps and Contact Lists****149**

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 the 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.”¹

—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