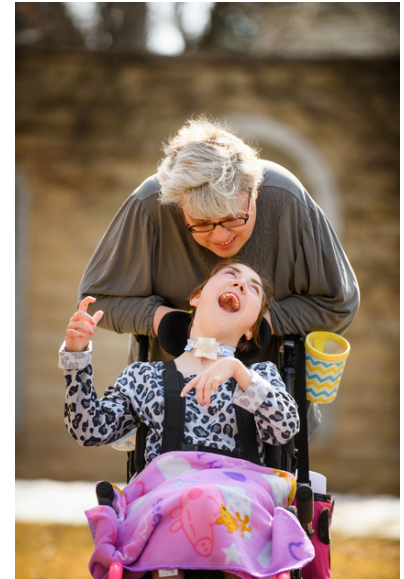


Partnering with Your Child's Health Care Team: TIPS AND TOOLS

As your child's most consistent caregiver, you know your child/youth with special health care needs (CYSHCN) in ways that no one else does. You having an active role as an equal member of your child's health care team is essential.

Developing partnerships with your child's health care team will help your child receive the best healthcare.

Start with clear communication between you and providers. Be sure to share any cultural preferences and identities that are important to your family's care.



KEEP A PHONE CALL LOG

Many families keep a notebook or online journal (like google docs) to keep a written call log of people you might speak with about your child. Write down the following information:

- Date and time of the call
- Name and title of the person you spoke with
- Person's phone number, email address and organization
- Reason for the call
- Information you were given
- Promised outcome or follow-up including the time frame for follow up

This type of documentation is very useful if you do not get the follow up promised or you need additional information. This type of information is especially important when working with insurance or county services.

WHEN APPLYING FOR PUBLIC PROGRAMS

- Keep copies of all information you send to County or State agencies in case information is lost or misplaced.
- If you fax, hand deliver, email or mail information get a receipt with the date it was sent. This is important in Minnesota when applying for Medical Assistance/ Medicaid/ TEFRA as payment for services are retroactive 3 months from the date you apply.
- Follow up with financial workers to determine that the information you sent was received and find out how long before a determination is made.
- Be sure to keep a record of the names and contact information of financial workers or case workers.
- If information is needed from your child's doctors, let them know that a request from the County or State will be coming and ask them to respond quickly.
- Keep copies of all written information you receive from County or State agencies or your child's insurance company.

KEEP NOTES ABOUT CHANGES

Keep a journal about changes or concerns about your child's health. This type of written documentation will help you relay accurate information about the changes you are observing. Be sure to date each entry, you may want to also include the time of day if that is relevant. Other things to record:

- Changes in vital signs, such as fevers, blood pressure, heart rate, etc.
- Eating, sleep, bowel issues
- Medication reactions
- Behavior changes

KEEP COPIES OF MEDICAL RECORDS

It can be helpful to request copies and read your child's medical records. If you are asking for copies from a hospital or from the clinic you may need to ask in writing and you may be asked to pay for the copying cost.

Some of the reasons to have copies of your child's medical records are:

- Review them for accuracy
- Gain a better understanding of your child's diagnoses and treatment
- Your child's records may be in multiple locations where care is received. You may have the most complete record.
- Having copies of lab work or previous x-rays can be helpful in communicating with specialists in different location or if you go to the emergency room.
- When applying for public programs or appealing insurance denials.
- You may be able to track changes, improvements or trends in your child's condition over time.

KEEP A CARE NOTEBOOK

Some parents find it helpful to use a 3-ring binder to keep copies of their child's important information so it is easily accessible when needed. It may be helpful to divide the 3-ring binder into sections and label them. Some suggested sections are:

- Current care plan Hospital discharge summaries
- Health history Insurance information
- Current and past medications Providers names and contact info.
- Lab and x-ray reports Education Plans

PROVIDE FEEDBACK and GET INVOLVED

- Tell your child's provider when you appreciate their efforts. It is also okay to let them know when something was not helpful, why and what would have been more helpful. Use positive examples about what worked well in another situation.
- Look for opportunities to provide on-going feedback such as joining a clinic or hospital family advisory committee.
- Family Voices has a Family-Centered Care Assessment Tool that might help you express what you are looking for in the health care system

familyvoices.org/fcca.