

How to Be an Effective Health Care Advocate



**Brought to you by:
The NC Family to Family
Health Information Center
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How to Be an Effective Health Care Advocate

Outline:

Module 1: Overview

Module 2: The 4 steps

Module 3: Equal partners (Medical Home)

Module 4: Acquire knowledge

Module 5: Improve skills

- a. Communication skills/listening
- b. Documentation/letter writing/record keeping
- c. Negotiation

Module 6: Participate and advocate



Module 1 Overview

In order to become an effective health care advocate, you must first know what an advocate is (and is not!), why you are the best person for the job, what you are advocating for, and how to advocate effectively.

Advocacy is speaking for another person or cause. An advocate is not an adversary or a bully! An advocate for a child (with or without a disability) can be a parent, a sibling, a relative, a provider or anyone!

What makes YOU your child's best health care advocate? You know your child better than anyone. You know your child's medical history and medical needs. You are there for the long haul. And, perhaps most important, YOU care the most!

To advocate effectively for your child you need a complete understanding of your child's disability and how that disability impacts his or her health care. You will need knowledge of laws and your rights. You will also need skills to use this knowledge productively.

In dealing with the sometimes complicated health care system, it's important to know what to advocate for and when. For this exercise, think of just one thing that needs your attention. It could be an insurance denial/appeal, a particular service or program or even a prescription.



Module 1 Worksheet

1. What is an advocate?

2. What I need to advocate for:

Example: Insurance approval

3. Why do I need to advocate?

Example: To get a service paid

Module 2

4 Steps

There are really just four steps to becoming your child's best health care advocate. Empower yourself with this knowledge and be ready to apply these skills!

1. Start with the assumption that you are an equal partner in the decision making process.
2. Acquire knowledge.
3. Improve your skills.
4. Participate and advocate.

4



Module 2 Worksheet

Word Scramble

Unscramble the words below that help describe the 4 steps of health care advocacy:

lisksl

tapicrapeta

luage

ernrtap

nwogedlek

teadcova



Word List:

EQUAL PARTNER KNOWLEDGE SKILLS
PARTICIPATE ADVOCATE

Module 3

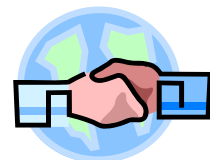
Equal Partners (Medical Home)

The Medical Home concept is the framework for establishing parents as equal partners with medical providers. A Medical Home is not an actual building, house or hospital but an approach to providing health care services in a high quality manner.

A "Medical Home" is defined as the primary care of infants and children that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. In a medical home setting, care is delivered or directed by well-trained physicians who provide primary care and help to manage essentially all aspects of pediatric care. The physician should be well known to the child and the family and should be able to develop a partnership of mutual responsibility and trust with them.

The five criteria for determining whether a family has a Medical Home are:

1. Having a usual place for sick/well care.
2. Having a personal doctor or nurse.
3. Experiencing no difficulty in obtaining needed referrals.
4. Receipt of family-centered care.
5. Receipt of needed care coordination.



As an equal partner in your child's health care you must be able to communicate effectively your views, feelings, and opinions to the provider, insurance carrier and others involved in the health care of your child.



Module 3 Worksheet

1. Where is your child's Medical Home?

Example: Lakeshore Pediatrics or Cabarrus County Health Department

2. Who is your child's regular medical provider?

Example: Dr. Jones (Family Practitioner) or Amy Jones, NP or Dr. Heart (Cardiologist)

3. Choose the level of difficulty you have in obtaining referrals for your child: (Choose one)

4. Does your child's provider include you in conversations about treatment for your child? (Choose one)

5. Does your provider communicate with specialists and obtain reports of visits with specialists? Note: If your child's Medical Home is with a specialist, do they provide reports back to the primary care provider? (Choose one)

Module 4

Acquire Knowledge

In order to become a successful advocate, you must acquire knowledge.

Learn everything you can about...

- your child's diagnosis.
- your insurance plan.
- federal and state regulations.
- agency responsibilities.
- how decisions are made.
- how to appeal decisions.
- state specific issues.
- how to find resources.



Obviously, if advocating with a medical provider the most important knowledge to have is about your child's condition. However, a lot of advocacy focuses on services, procedures, prescriptions etc. which will require advocating with an insurance company.

The best way to advocate with an entity such as an insurance company is to prepare yourself by being able to "speak the lingo". Understand exactly what your policy covers and what it does not. This holds true for public health plans, such as Medicaid, as well. Learn their appeals process including time frames on when things need to be turned in for consideration. Often, an insurance company will only allow 60 days for an appeal to be considered.

Arm yourself with a list of resources specific to your situation. Websites for various insurance companies will provide a wealth of knowledge. State agencies have websites too! If you are unsure about how to find resources for your needs, give us a call at the NC Family to Family Health Information Center for direction (800) 962-6817 ext. 35.



Module 4 Worksheet

Checklist:

- Learn all you can about your child's diagnosis.
- Know where your insurance book is located!
- Read your insurance handbook.
- Learn the insurance "lingo".
- Know exactly what your coverage includes.
- Know what the appeals process is for your plan.
- Know who to call for help.

Hint:

NC Family to Family Health Information Center
(800) 962-6817 ext. 35

Module 5

Improve Your Skills



a. Communication/Listening

One of the more important attributes a good advocate must have is the ability to communicate. Be able to express yourself clearly. The other necessary skill that goes along with communication is listening. Be able to ask the right questions and really listen to the answers. The methods of communication include: spoken, written, non-verbal (includes body language) and listening.

A good way to begin is to plan ahead by making a list of the issues. Put them in order of importance and know which ones you are willing to let go if necessary. While preparing this list, have options and ideas for solutions in mind. Offer them for discussion.

Be ready to paraphrase...“in other words...”
summarize...“let’s make sure I understand...”
and outline... “my position is...”

Actively listen to understand. If you don’t understand what is being said, ask for more information! Ask to have it explained to you in a different way or if there is something you can get in writing. Resist the temptation to answer your own question or put words in someone else’s mouth.

Check your body language, even on the phone. A smile comes across the phone! If in person check the messages you are sending with your body. Do you seem interested? Bored? Angry? Distrustful? It’s hard to shake hands with a clenched fist!

Module 5 Cont.



a. Communication/Listening

Watch those emotions! Keep focus positively on your goals. Keep negative thoughts of past or present issues from creeping into your mind and be positive about succeeding. Say what you want to say but avoid whining, pleading, screaming and sarcasm.

Expressing our wants, feelings, thoughts, and opinions clearly and effectively is only part of the communication process. The other part is listening!

10 Steps to Effective Listening:

1. STOP talking!
2. Put the other person at ease.
3. Show them you want to hear them.
4. Remove distractions.
5. Empathize with the person.
6. Be patient.
7. Watch your own emotions.
8. Be slow to disagree, criticize, or argue.
9. Ask lots of questions.
10. STOP TALKING!



Refer to PowerPoint!

6 Barriers to Listening:

1. The opinions are different from yours.
2. You have had the conversation before.
3. You don't like the person.
4. The person is saying something you don't want to hear.
5. You feel anxious or the comments cause stress.
6. The person is making a request of you, your time, or your resources, which sounds like a demand.



Module 5 a. Communication/Listening Worksheet

1. One of the most important attributes a good advocate must have is the ability to _____ . (Fill in the blank)

2. The methods of communication include: (Fill in the blanks)

3. Matching: (Make your selection from the drop down box)

Outline

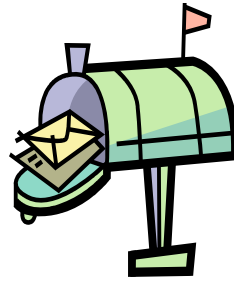
Summarize

Paraphrase

4. List the 10 steps to effective listening:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Module 5 Cont.



b. Documentation/Letter Writing/Record Keeping

Admittedly it is much easier to pick up the phone and make a request of your child's provider or your insurance company. There are advantages, however, to making those same requests in writing. By providing your request in writing you are prompting the receiver to provide their answer in writing. This is the best way to start your "paper trail".

In negotiation, which will be covered a little later, it's often important to have a paper trail of documentation. It's sometimes your only proof. Keep your request short and simple and always date your letters. Email works too! If you do choose to send your request via regular mail, make sure you keep a copy for your records.

Always follow up on conversations or meetings with a note or letter. Be sure to thank the person for their time. Restate what was discussed and decided or what you are asking for. When asking for something specific, include a time frame for a response back to you and also the best ways to reach you.

When writing a letter, give the facts. Avoid letting your anger, frustrations, blame or negative emotions show in your words. After you've written your letter, save it for a day or two, then re-read it with "fresh" eyes. Also, re-read the letter as if you were the one receiving it and it's always a good idea to let someone else read it too. Make sure your message is clear and that you included important facts. Use spell check or ask a friend to help you edit. Remember to keep a copy!

Module 5 Cont.

b. Documentation/Letter Writing/Record Keeping

Start keeping a record of past requests, explanations of benefits, denials letters etc. This will help you stay organized, document progress or needs, and support future requests. It's even more helpful if your records are in chronological order. Your requests have a better chance of being considered if you have the documentation to back you up!

If you are just starting a record keeping system, include:

1. medical records
2. school records
3. insurance information
4. letters
5. observations/notes
6. log of calls/emails/letters etc.



One resource we like to share is on the American Academy of Pediatrics website. If you follow the link below you can pick and choose your own pages to build your own "Care Notebook":

<http://www.medicalhomeinfo.org/CareNoteBook/>



Module 5 b. Documentation/Letter Writing/Record Keeping Worksheet

1. It's always a good idea to make your requests in writing.
(Choose one)

2. You should never date your letters.
(Choose one)

3. List three things you should include in a follow up note:

4. If you are angry about an issue you should express that in a request letter. (Choose one)

5. List three ways record keeping will help you:

6. List three things you should include in your record keeping system:

Module 5 Cont.

c. Negotiation

There are seven elements of negotiation which include:

1. Interests- the concerns, wants, needs, hopes and fears that underlie and motivate the positions.
2. Options- possible ways of dealing with the issues.
3. Alternatives- what can happen without an agreement?
4. Legitimacy- what makes an agreement fair? How do we measure?
5. Communications- effective speech and active listening.
6. Relationships- the pattern of interactions over time.
7. Commitments- statements of what each party is willing to do in the future.

Remember that negotiation is a *process* for resolving disputes. It can include bargaining for an advantage and then agreeing upon a course of action.

Successful negotiations will include benefits for both parties and end as a win-win situation.



Module 6 Participate and Advocate

In order to become an effective advocate it is necessary to actually participate! Informed family participation and planning in all decisions such as finding a Medical Home and health care plans for school age children require your attention. Become an active and visible presence in the health care of your child. Some examples of how to do this include: asking clarification questions of the medical providers, including yourself in Individual Health Plan meetings with your child's school nurse and "shopping" for a Medical Home.

Must have skills for advocates:

1. Identify the problems and propose solutions.
2. Plan ahead and prepare for success.
3. Keep written records.
4. Build working relationships.
5. Pay attention - gather and use information to make decisions and requests.
6. Understand or learn how federal, state, and local "systems" operate.
7. Communicate effectively- ask the right questions and really listen to the answers.
8. Assume that everyone involved cares about the health of your child.
9. Be optimistic about reaching an agreement.
10. Leave your "personal baggage" at home.
11. Know what YOU want for your child.
12. Know that there are NO personal issues.
13. Be assertive.
14. Become a win-win negotiator.
15. Keep records of all documents and log all calls.



Get your facts straight before you take an action!

Wrap Up

Tips for success:

1. Look for solutions rather than placing blame
2. Acknowledge interests and ask the questions that will help identify any underlying barriers.
3. Stay positive and "future focused".

If you get stuck try asking if someone can go over all the options that have been presented or if there are other resources that can be brought in to help us work this out.

Remember that some people are just more difficult to work with than others. Always take the high road. Respectfully but effectively work around them!

It is important to remember that you are building relationships with those that have an interest in your child's health. These relationships can last for years. Even if it's just a voice on the phone, be polite!

You are only human. If you make a mistake or cause offense, say you are sorry! Acknowledge what has gone well. Always remember to thank people for their time, efforts and concern.



Don't forget to complete your evaluation in order to obtain your certificate of completion!