Stop Spinning Your Wheels:
Advocacy and Coordination Skills for Your Special Health Needs
(Medical Home)
1. What Advocacy Is
2. Why it is Important
3. Key Advocacy Skills
4. Medical Home (Comprehensive Coordinated Health Care)
5. Getting Organized – Creating a Care Notebook
6. Resources
What is an Advocate?

Advocates speak up for themselves or others to make things better.

Have you ever?

• Met with your teacher about any issue?
• Spoke at a local gathering about a project you care about?
• Told a cashier that an item was not ringing up correctly?
Use Your Power

• “The most common way people give up their power is by thinking they don’t have any.”

—Alice Walker
Why be an Advocate?

• Your experiences are valuable and can be used to improve things
• You know when something is or isn’t working
• You have ideas how to make things better
• You have the only long-term connection
Six Skills

To be an effective advocate:

• Understand the disability
• Know the key players
• Know your rights and responsibilities
• Become well organized
• Use clear and effective communication
• Know how to resolve disagreements
Skill #1: Understand the Disability

**Understanding helps you:**

- Know which services are appropriate
- Have high expectations
- Find the right assistive technology and accommodations

**Use resources to learn more!**
Skill #2: Know the Key Players

• Who is the director or decision maker?
• Are staff people public, non-profit, or private employees?
• How can you find a person’s name?
In Other Words:

• Who is the “star”?  
• Who are the players?  
• What are the rules?  
• What is my plan of action?  
• What do I say when it’s my turn?  
• What do we do when we disagree?
Skill #3: Know Your Rights and Responsibilities

Learn about them by:

- Reading Web sites
- Asking how service is funded
- Asking to see laws and policies
- Asking questions
- Joining a group
Skill #4: Become Well Organized

- Keep records
- Put it in writing
- Keep a phone log
- Have a meeting notebook
Skill #5: Use Clear and Effective Communication

• Keep your eyes on the “prize” – the right services!
• Listen and ask questions
Skill #6: Know How to Resolve Disagreements

Informal Processes:

• Talk to people first
When You Disagree

• Disagree without being disagreeable
• Apologize if needed
• Separate the person from the problem
• Realize NO ONE has all the answers
• Make sure your facts are correct
• Choose your battles
Parents as Partners

Parents and professionals can be partners and:

• Work together
• Share goals
• Have individual roles
• Share authority
• Have different skills
• Solve problems
Tips for Good Communication at a Meeting

- Focus on your goal
- Show respect and expect it from others
- Manage your emotions
- Ask questions
- Rephrase for clarification
- Say thanks
Tips for Written Communication

Letters should:
• Be sent to person who can make a change
• Be dated and signed
• Focus on one or two issues
• Be no longer than one page
• Set a deadline if a reply is requested
• Give your contact information

Remember to keep a copy for yourself!
Advocacy within your Medical Home

My What?
What is a Medical Home?

• It is not an actual place or building you can go to. The word home means that you have a “home base” for your health care needs.


National Center for Medical Home Implementation –
Definition of Children and Youth with Special Health Care Needs

• Children and youth with special health care needs (CYSHCN) are defined by the Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as:

  “those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

• This definition is broad and inclusive, and it emphasizes the characteristics held in common by children with a wide range of diagnoses.

Who Are Children with Special Health Care Needs?

Prevalence of Special Health Care Needs in Children and Youth

- Childhood disability is increasing and that emotional, behavioral, and neurological disabilities are now more prevalent than physical impairments.i
- Approximately 10.2 million children in the US, which represents 15 percent of all US children, have special health care needs based on the MCHB definition;ii
- More than a fifth of US households with children have at least one child with special needs;
- 16 percent of CYSHCN are reported to not receive all the services they need;
- More than 94 percent of CYSHCN have a regular source of care when they are sick. For 78 percent this is a private doctor's office; for 13 percent it is a clinic or health center; and for almost 4 percent it is another setting.

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i The Future of Children, Spring 2012
ii 2009/10 National Survey of Children with Special Health Care Needs

2009/10 NS-C SHCN: Condition Specific Profiles
7 Key Elements of a Medical Home

1: Accessible
2: Family Centered
3: Continuous
4: Comprehensive
5: Coordinated
6: Compassionate
7: Culturally Competent
There is high-quality care available when you need it, and insurance is accepted (including Medicaid).
**Family Centered**

- The doctor treats you as a partner and shares information about your care.
The same pediatrician or family doctor sees you all the time and helps you transition to adult care when ready. Your doctor helps you and/or your child deal with other changes (transitions) such as changing schools, getting a job, or going to college.
The doctor arranges to have someone available to see you 24 hours a day, seven days a week. Your doctor can see you in the office, or hospital when needed. Your needs for home health and/or hospital care are discussed with you.
The doctor’s office talks to the specialists that you see, helps with your school plan (Individualized Education Plan - IEP), gives you information about community resources and makes referrals when you need them.
Compassionate

The pediatrician or family doctor shows concern and caring toward you, your family, and your child.
The pediatrician or family doctor includes your religious and cultural background in planning care with you and your child.
Small Group Activity
Your Child’s Medical Home

• What Medical Home Qualities Are Important to You?
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
  • _______________________________________________
My Ideas About Medical Home

I wish my child’s current medical provider would...

- ____________________________________________
- ____________________________________________
- ____________________________________________
- ____________________________________________
- ____________________________________________
- ____________________________________________
- ____________________________________________
- ____________________________________________
This is Important to Me Because

- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
- ____________________________
Care Coordinators in the Medical Home

- Assist with:
  - EPSDT
  - Genetics and Screening Referrals
  - Family Partners
  - Family Supports
  - Secondary Transition
  - Additional Resources
    - See Handouts
Creating a Care Notebook
What is a care notebook

• A care notebook has multiple uses. A major role of a care notebook is to help parents/caregivers maintain an ongoing record of their child's care, services, providers, and notes. This care notebook is a great tool in empowering families to become the experts on their child's care. It is also a way to maintain the lines of communication between the many providers and services that help care for a child and their family.

• Health professionals recommend that parents/caregivers bring a care notebook to all medical appointments, therapies, care conferences, on vacations, etc. Health professionals can encourage the use of these notebook by either having them available at the first office visit, upon discharge from the hospital or in the waiting room on a resource table. This notebook should be a team responsibility. Office staff should offer families assistance in filling out the various forms. Medical offices can copy visits, check ups, immunization records, specialist reports, clinical pathways, and give them to families to insert into the notebook.
How do I build my own care notebook?


- Twenty Care Notebooks have been divided into sections with similar content and made available in both Microsoft Word and PDF formats. You can fill-in and print completed PDF forms from the Web site or print blank forms and complete them manually. Most people will want to fill-in and save the Care Notebook documents and this is most easily done with the Word documents. Those who do not have Word software are able to use the PDF format version with the understanding that the forms cannot be altered (or changed). It is recommended to view the online examples before building your own care notebook.
Why Build Your Own Care Notebook

• A care notebook is an organizing tool for families and will help you keep track of important information. Care notebooks are very personal to your child and ideally should be customized to reflect your child's medical history and current information.

• http://cshcn.org/sites/default/files/webfm/file/Care_Notebook/CareNotebook-AllDocuments.pdf
Resources and Websites of Interest


- Family Voices National - Homepage for the national advocacy organization. [http://www.familyvoices.org](http://www.familyvoices.org)


Summary

“I am only one, but still I am one. I cannot do everything, but still I can do something. I will not refuse to do the something that I can do.”

—Helen Keller
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Contact Information

Idaho parents Unlimited
500 South 8th St.
Boise, Id. 83702
208.342.5884
208.342.1408 fAX

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PACER.org | 952.838.9000 | 888.248.0822