



Fostering Children and Youth with Special Health Care Needs

Fostering a child or youth with special health care needs can be an incredibly challenging and rewarding experience.

An experienced Wisconsin foster parent said that one of her greatest joys is seeing a child accomplish something that no one thought was possible.

As a foster parent of a child with special health care needs, you may see a newly acquired skill as being huge in terms of the child's development, whereas others might take it for granted and just expect it.

With the great joys, also come the challenges of trying to learn about each child's specific health care needs and how to best care for those needs.

As a foster parent, you may have nursing staff coming into your home to assist the child with their cares, using specialized medical equipment, and attending numerous medical appointments with various specialists. In essence, you become an advocate and the knowledge hub of information—often keeping the parents, case manager, doctors, teachers, and therapists up to date with critical information.

Navigating the Medical Health Field

Some newer ideas are “the medical home” and “care notebooks.” The medical home is *not* a home at all, but more of a philosophy. It means

that the doctors' office provides coordination and comprehensive care for a child with special health care needs.

Your doctor's office will assign a **care coordinator**, who will work to help coordinate services for the

child. Not all doctors offices in Wisconsin have this service yet. For more information on the medical home, see:

<http://dhs.wisconsin.gov/health/children/medicalhome/index.htm>

The idea of a *Care Notebook* comes directly from the medical home initiative. A care notebook

is a notebook of medical information that helps parents maintain an ongoing record of the child's care, services, providers, and notes.

A care notebook will hopefully further increase the team approach in caring for a child's special health care needs and improve communication among all service providers. For more information about care notebooks, see http://medicalhomeinfo.org/tools/care_notebook.html

Strategies for Working with Medical Staff

Even though it's easy to be intimidated by the “professionals,” don't be afraid to ask questions. Try to learn how the system works, including learning about the child's team and their roles.

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Ask for specifics to be on the agenda, or better yet, *you* create the agenda and take a lead role in meetings. Try to have someone come with you whose job is only to take notes and be supportive.

Agree on a regular type of communication: phone, e-mail, fax, etc. Email is particularly good (if all are able to use it) because everyone only has to say things once and everyone is all on the same page—literally!

If you find yourself getting frustrated, try to find positive ways to get your point across. You might also repeat information back to make sure you understand and heard things correctly. And ask others to repeat what your perspective is.

Tips for Being an Effective Advocate

Part of working with medical staff—or any team—is being an effective advocate. You might want to try the following.

- Do your research and learn about the specific issues.
- Prepare ahead of time. Write down questions you want to ask before the meeting.
- Follow up meetings with thank you letters or emails.
- Have the confidence to ask the tough questions.
- Listen to what is being said both verbally and non-verbally at meetings.
- Try and check your personal feelings at the door and focus on sharing information.
- Figure out what the main issue is and then practice telling how it directly effects the child.
- Think of solutions in terms of meeting the needs of the child and solving the issue.

10 Resources for Fostering Children with Special Health Care Needs

1. **CYSHCN** (Children and Youth with Special Health Care Needs Program)
<http://dhs.wisconsin.gov/health/children/>
2. Special education services advocacy organizations:
 - **FACETS** (WI Family Assistance Center for Education, Training, & Support) <http://www.wifacets.org/>
 - **WISPEI** (Wisconsin Statewide Parent Educator Initiative) <http://www.wi-pec.net/WSPEI.htm>
3. **Birth to Three**
<http://dhs.wisconsin.gov/bdds/birthto3/>
4. **FCARC** (Foster Care and Adoption Resource Center)
<http://wifostercareandadoption.org/>
5. **Parent to Parent Services and Resource Centers**
<http://dhs.wisconsin.gov/health/children/resourcecenters/index.htm>
6. **WFAPA** (Wisconsin Foster and Adoptive Parent Association) <http://www.wfapa.org/>
7. **County Health Departments**
<http://dhs.wisconsin.gov/LocalHealth/>
8. **Wisconsin Department of Health Services**
<http://dhs.wisconsin.gov/bdds/index.htm>
9. **Transition Resources for students with disabilities**
<http://dpi.wi.gov/sped/transition.html>
10. **Childcare and Respite Resources**
<http://dhs.wisconsin.gov/health/children/resourcecenters/index.htm>

Know ahead what compromises you are willing to make.

- Ask for additional support if you need it. There are some wonderful support groups and resources available.

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Five Language Tips

Another strategy that may help you when working with teams or when trying to educate your friends and families is paying attention to the words you use.

Most of us take language for granted or think that the “politically correct police” are out to get us. But the way we use words says more about us—and others—than we think.

Here are some points to keep in mind:

1. **Be informed.** Use the most current and up-to-date terminology. For example, use disability instead of handicapped.
2. **Be positive.** Focus on the child’s abilities and only use the diagnosis if necessary
3. **Use “people first” language.** If you need to say the child’s diagnosis, start with the child’s first name, then the diagnosis. For example, Jon is a child who has autism, not “Jon is an autistic child.” And even, “Jon is a child in care.” Not “Jon is a foster child.”

4. **Be respectful.** Only talk about the child’s disability if you need to; nobody likes to constantly hear about being different.
5. **Be sensitive:** words like “normal,” “regular,” and “problems” can have a negative connotation. Consider using “typical,” “challenges” and “abilities” instead.

One of the greatest things about fostering a child with special health care needs can be that unexpected smile or twinkles from their eyes.

“It’s easy to be consumed with caring for specialized medical needs,” says a Wisconsin step mother. “But despite the challenges, these kids are still kids and they want to do the same things that kids do, just on a level that is attainable for them. Take joy in doing the simple things like reading a book or playing a game. It can help you see your child as a child and not as a diagnosis.”



Foster Care & Adoption Resource Center life Library Resources

- **Child with Special Needs (The)** by Stanley Greenspan and Serena
<http://www.wifostercareandadoption.org/plugins/library/viewmaterial.asp?aid=5140>
- **Meeting the Challenge: Parenting Children with Disabilities** (VHS)
<http://www.wifostercareandadoption.org/plugins/library/viewmaterial.asp?aid=4820>
- **Issues of Parenting and Advocating for Disabled Teenagers (Tape)** by N. Umbach
<http://wifostercareandadoption.org/plugins/library/viewmaterial.asp?aid=4023>
- **Three R’s for Special Education: Rights, Resources and Results** (VHS)
<http://wifostercareandadoption.org/plugins/library/viewmaterial.asp?aid=4888>

Other Resources

Build Your Own Care Notebook, American Academy of Pediatrics
http://www.medicalhomeinfo.org/Tools/care_notebook.html

What is a medical home? American Academy of Pediatrics
<http://www.medicalhomeinfo.org/>

Wrightslaw: From Emotions to Advocacy, 2nd Edition by Pam Wright & Pete Wright
<http://wrightslaw.com/bks/feta2/feta2.htm>

Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations, by Judy Winter
<http://www.judywinter.com/>