

Advocacy



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Emily Needs More School Services

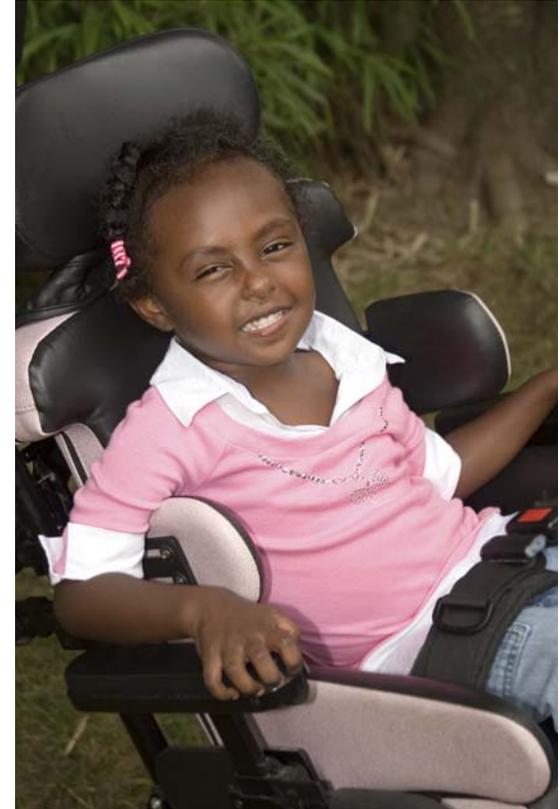
Emily is 9 year old with many medical conditions. She has mild cerebral palsy (CP), diabetes, a learning disorder, and is fed through a G-tube. Emily is in 4th grade. At the beginning of the school year Emily's parents went to her IEP (Individualized Education Program) meeting. At the meeting the family met Emily's teachers and therapists to make the yearly plan for her special education and health care needs.

Emily's school plan includes Special Education, school nursing services, speech therapy, and adaptive physical education. She did not qualify for PT (Physical Therapy) or OT (Occupational Therapy) services at school.

Emily spends the morning in a regular class and the afternoon in a Special Education class. The Special Education teacher helps Emily with her behavior, homework, taking tests. She goes to an adaptive gym class because of her CP. Emily sees the school nurse at noon every day for G-tube feedings, blood sugar checks, and insulin shots. She also gets Speech Therapy once a week.

Recently her mother has noticed that Emily falls more often, loses her balance, and has difficulty writing. Emily told her mom that she feels clumsy and different from the other kids. Because of these changes Emily is starting to withdraw socially and emotionally at school. When Emily's mom asked her teachers about this, they told her that they have noticed these changes too. Emily's mom told the teachers that she wishes Emily could get more services at school, but the school has not contacted her about making changes. She feels frustrated and does not know what to do next.

- What can Emily's mom do to advocate for Emily's school needs?
- Where can she learn more about how to advocate for Emily at school?



What's It All About

Advocacy means speaking up and acting in support of your child and family. When you advocate you are taking responsibility, sharing in decision-making, and being a full member of your child's care team. Advocacy includes:

- Knowing what your child needs.
- Knowing your child's rights.
- Promoting your child and family's best interests.
- Knowing when to compromise.
- Knowing when to take things to the next level.

All parents, whether or not their child has special health care needs, are advocates. As your child's advocate you are responsible for making sure your child gets what is needed. Sometimes your child needs you to advocate more than usual. You may have to speak up for your child or disagree with others. Many caregivers feel uncomfortable with this level of advocacy at first. It takes time and experience to develop skills.

You know more about your child than anyone else. Sometimes caregivers think doctors, nurses, teachers, and others are smarter or more powerful. It is important to feel confident that what you say will make a difference. Teachers and health care providers are experts in a certain area such as education or medicine. You are an expert about your child. Sharing your thoughts and concerns and listening to others can help your child. When you advocate and work with others, your child is more likely to get needed care and services.

Becoming an effective advocate helps in all areas of life. Some of the benefits of advocacy are gaining a sense of control, increasing your confidence, feeling satisfied with care and services, and developing communication skills. Your actions can range from helping your own child to helping other families, advocating for a policy change, or speaking up for larger causes.

Steps to Learning about Advocacy

1. Identify the advocacy goal.
2. Find out the options.
3. Choose the best option to help your child.
4. Find resources that can help.
5. Communicate, problem solve, and negotiate to meet your child's needs.

Take Action

Talk with your health care provider.

Identify the advocacy goal.

To advocate successfully you need to be able to tell other people what the need is, what the possible options are, and why you believe one option is better than the others. It is important to think about each of these steps. You can use the Advocacy Action Plan, Form 11.1 to keep track of what you do.

List why the goal or need is important.

An action plan describes the need. Think about your child's goals and quality of life. Describe how the problem interferes with reaching goals. For example, your child needs a power wheelchair to be more independent and you need to advocate for the insurance company to pay for it.

- How does it affect daily life?
- Do other people see the need? What have they said?
- Does anything make the problem better or worse?
- How could you give clear information about the need?
- Are there other ways the need could be met?

Find out the options.

Get information from as many sources as possible. Think of anything that could make daily life better. This will give you the most complete list of options. For example, if you think your child is too tired in school, talk with the teacher, aide, school nurse, and gym teacher to get their ideas for what would help.

Choose the best option to help your child.

After you have put together a list of your options, start to compare them. Think about which options are possible and how they will affect your child and family. Each option has pros and cons. Describe all the options and ideas for supporting the need. You can use the Decision Guide, Form 11.2 to help you compare options and make the best choice for your family.

- Pick the options you prefer.
- Be specific about what you want to happen.
- Tell why those options are better than others.
- Consider the pros and cons of each option.
- Think about how each option impacts daily life.
- What matter most to your family?
- Get opinions from family members and other people important to you.
- How will you know if that option helps?

Take Action

Talk with your health care provider.

Find resources that can help

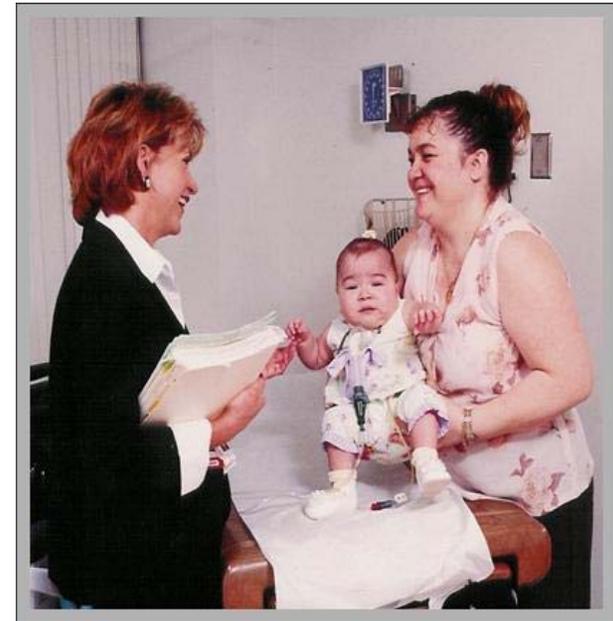
Think about what resources are needed. You might get help from schools, community agencies, resource centers, advocacy groups, insurance companies, literature, the Internet, or other parents.

- Do you have those resources available?
- Do you want someone to help you?
- Do you need written information?
- Is there an expert you can turn to?

Find out who the right person is to work with you to get the service or care that your child needs. Start with the person that works directly with your child or service. For example, talk with the teacher before going to the principal, or start with a customer service representative before asking for a supervisor. If the first person that you work with is not able or willing to help, you can ask to speak with a supervisor or someone with more authority.

Tips for advocating after something goes wrong

- What is the problem? Describe what has happened and what are you concerned about.
- What questions do you have? What went wrong?
- What are your ideas for making things better?
- What do you want them to do?



Take Action

Talk with your health care provider.

Communicate, problem solve, and negotiate to meet your child's needs.

If what you are doing does not work, try something else. Even though you made best decision at the time, you may need to look at other options. Try to find other resources and information to help you continue to advocate for your child's needs. You will need to keep open communication with others involved. This keeps the doors open for compromise and problem solving to get what's best for your child.

Remember, whenever possible your child should be involved in making decisions. For example, their opinions should be considered when deciding about medical treatments.

Encouraging your child's voice

- Teach child about condition and include in giving treatments.
- Teach how to recognize changes in condition and what to do.
- Have child share information and ask questions at appointments.
- Involve in school meetings.
- Request child's ideas, concerns, and goals when making decisions.
- Teach how to make decisions and solve problems.
- Encourage independence: chores, budgeting, using transportation.
- Help them build social skills through friends, school activities, peer tutoring, volunteering.

Check Yourself

- Identified the advocacy goal.
- Found out the options.
- Chose the best option to help my child.
- Found resources that can help.
- Communicated, problem solved, and negotiated to meet my child's needs.



More Information and Resources

Family Advocacy

- **Family Voices of Wisconsin:** Network of families with children and youth with special health care needs, provides information, training, and leadership opportunities. www.fvofwi.org
- **PACER Webinar Series:** Educational videos with many topics about children with disabilities: <http://www.pacer.org/webinars/archive-listing.asp>
- **Parent Technical Assistance Center Network:** Training, information, and assistance to families of children with all disabilities ages birth to 26 years: www.parentcenternetwork.org
- **Guardianship and Alternatives to Guardianship:** Download booklet of legal information about guardianship: http://www.ridlc.org/publications/Guardianship_and_Alternatives_To_Guardianship_Booklet.pdf
- **National Disability Rights Network (NDRN):** Protection and advocacy for people with disabilities: www.napas.org
- **Children's Disabilities Information:** Articles and resources to empower parents of children with disabilities and special needs: www.childrensdisabilities.info

Education Advocacy

- **School Accommodations and Modifications:** Download information sheet: <http://www.parentcenternetwork.org/assets/files/national/all15.pdf>
- **Special Education Rights:** Resources and videos about special education: <http://www.pacer.org/publications/specedrights.asp>
- **Special Education in Plain Language:** User-friendly interactive handbook on special education laws, policies and practices in Wisconsin: <http://www.specialed.us/pl-07/pl07-index.html>
- **Parent Educational Advocacy Training Center:** Resources for advocating about special education: http://www.peatc.org/peatc.cgim?template=special_education

More Information and Resources

Health Care Advocacy

- **Speak Up Initiatives:** Joint Commission series of brochures, videos, and other information about being involved in your health care: <http://www.jointcommission.org/speakup.aspx>
- **Families USA Advocacy Tools:** Information, toolkits, news updates, and more for health care advocacy: <http://familiesusa.org/resources/tools-for-advocates/>
- **Children's Defense Fund:** Nonprofit agency that advocates for support of children about topics including poverty, abuse and neglect, and access to health care: www.childrensdefense.org
- **Special Needs Alliance:** National nonprofit with lawyers specializing in public benefits and disabilities: www.specialneedsalliance.org
- **ABC for Health, Inc:** Public interest law firm providing benefits advocacy and counseling for families: www.safetyweb.org
- **Wisconsin Statewide Parent-Educator Initiative:** Parent Liaisons that have received training about special education: http://dpi.state.wi.us/sped/par_liaison.html

Self-Advocacy

- **Your Personal Passport:** Workbook to download, for disabled people to share what is important to them to be involved in planning for their own lives: <http://www.allenshea.com/AllStatesPassport.pdf>
- **KASA (Kids As Self Advocates):** National grassroots project created by youth with disabilities: fvkasa.org
- **Be Your Own Best Advocate:** Download Information sheet: <http://www.pacer.org/parent/php/PHP-c116.pdf>
- **How to Tell Your Story to the Press:** Tips before you talk to the media: <http://www.survivorshipatoz.org/hiv/topics/media-how-to-get-press-coverage/>

Advocacy Forms

Form	How it can be used
Advocacy Action Plan 11.1	Use this form to make a plan to advocate for your child and family.
Decision Guide 11.2	Use this form to help you compare options and make the best choice for your family.

Advocacy Action Plan

Use this form to make a plan to advocate for your child and family.

What is the goal or need?

What options could meet the goal or need?

Which option is best? Gather information to support your choice.

What resources can help (such as other parents, resource centers, health care providers)?

Who has the authority to make changes to meet the need?

Next steps

Decision-Making Guide

Use this form to help you help you compare options and make the best choice for your family.

Decision					
What decision do you need to make?					
When do you need to decide?					
How involved do you want to be in the decision?					
<input type="checkbox"/> I want to share the decision with: <input type="checkbox"/> I want to decide after hearing the opinion of: <input type="checkbox"/> I want someone else to decide:					
Options List the Pros (things that are good about that option) and Cons (things that are bad about that option). Then rate how much it matters to you from 1 (lowest) to 5 (highest).					
	Pros	How much it matters	Cons	How much it matters	Questions or Information needed
Option 1					
Option 2					
Option 3					
Support					
Do you have enough support and advice from others to decide? <input type="checkbox"/> Yes <input type="checkbox"/> No					
Who else is involved in the decision?					
Which option do they prefer?					
How can they support you?					
Next Steps					
Things you can try:					
Need more information	<input type="checkbox"/> Note where or who can help you find answers to your questions and get more information.				
Need support	<input type="checkbox"/> Discuss your options with a trusted person. <input type="checkbox"/> Find out what resources can support your choice (e.g., money, transportation, child care). <input type="checkbox"/> Share your decision guide with others. <input type="checkbox"/> Find a neutral person to help you and others involved.				
Need to know what's important to you	<input type="checkbox"/> Review the pros and cons list to see what matters to you. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Discuss with others what matters the most to you.				
Other things that could help with the decision:					