Why Your Child Needs You to Become an Advocate

What is an advocate?

An “advocate” can be broadly defined as “someone who speaks up on behalf of others to make things better.” Advocacy covers a very broad range of activities that just about everyone, in many settings, does every day. Most of us have advocated for others. As a parent of a child with a disability, you have already had to speak on behalf of your child, possibly to a teacher, day care worker, doctor, nurse, social worker, other parents, relatives, or friends.

One parent of a child who is blind said, “I am a private person, and I do not like to speak up. But I saw my child was not going to be served appropriately unless I did speak up.”

Advocacy is a parent’s right and responsibility

Your child needs you to advocate for him or her in the area of education. Parents have a legal right and responsibility to advocate for their children with disabilities. The federal special education law, IDEA (Individuals with Disabilities Education Act), requires parent participation1. The special education services for a child are developed in a decision-making process involving the child’s parents and school district staff. 2

The professionals are qualified to serve your child by reason of their education; you are qualified to advocate for your child by reason of your role as the parent. You are the only person on the team who knows the complete child: how the child functions at home and in the community, the child’s medical and academic history, and your child’s interests, preferences, and desires.

Some parents may feel they face additional barriers. Some have told us, “We come from a different culture; in our native country, we were not involved in our children’s education, and we are not used to talking and asking questions,” and “It is hard to advocate for my children when I don’t know what to ask for or what services are available to them.”

Professionals have knowledge and expertise in a specific area, but they are only a temporary part of your child’s life; you will always be the parent. You are the only permanent member of your child’s Individualized Education Plan (IEP) team, at least until your child turns 18 3. Professionals deal with many children, while you only have your child to think about. Your child is served best if you and professionals work together.

Make a decision to advocate

Advocating for your child becomes easier when you make a decision to be an advocate for your child. For example, Carolyn Anderson, PACER parent advocate and parent of a child with a disability, says, “I was a very shy person until I became the parent of a child with disabilities. I decided I was going to have to speak up at meetings so my child received the services he needed. This has not been easy, as shyness is part of my basic personality. But I made a decision that speaking up on behalf of my child was important enough for me to know I needed to change. People who know me now have no idea what a shy, private person I used to be!”

“Like most parents, I knew nothing about my child’s disability. Once the disability was diagnosed, I read everything I could find and talked to everyone who seemed to know anything about it. I learned that there were differing opinions
on how to work with children with this disability. One method of educating and rearing a child with this disability was most popular with the school system, but I realized I needed to decide what I thought was the method that would work for my child."

“After considering that method and my vision for my son, I decided that the popular method was not appropriate for him. I would need to advocate for something different if I wanted my child to achieve the dreams I had for him. I decided to challenge myself to speak up when I’d rather sit back and be quiet. It wasn’t easy, and it took a number of years before I was comfortable in my new role, but it was worthwhile. My son has done more than I ever envisioned.”

Advocating for your child with a disability is one of the most important jobs you’ll ever have and can have lifelong implications. For starters, no one understands your child like you do. You know his or her strengths, challenges, spirit, and dreams better than anyone. You have a vision for your child’s future and a sense of what it will take to achieve it. You have opinions on what is working and what is not. Your IEP team members need you to provide this information to help them support the IEP’s goals and objectives with the vision you have for your child.

Not only do you have a unique understanding of your child, you also have a lifelong connection. Once your child grows up, the people from school will be gone. You will be left with the results, so it’s important to make sure they are the ones you and your child want. Advocating for your child over the years can help ensure that outcome.

**Model self-advocacy**

You might not realize it, but every time you stand up for your child’s rights and speak out for his or her needs, you are modeling an essential skill: self-advocacy. By watching you at IEP meetings and seeing how to effectively express needs and opinions, your child will have the opportunity to learn a vital skill that will be important for a lifetime.

In the end, advocacy is all about making sure your child receives the services and education which he or she needs and is entitled to. As Virginia Richardson, PACER parent training manager, says, “You are the person who holds the hope for your child’s future. This involves speaking up on his or her behalf.”

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1 According to IDEA, parent includes biological and adoptive parents, in some cases foster parent, legal guardian, individuals acting in the place of the biological or adoptive parent, and individual legally responsible for the child’s welfare. If a child does not have a parent, the school is required to appoint someone (a surrogate) to represent the child.

2 If English is a second language for you, realize that an interpreter is required so that each side can understand the other. Interpreters are not just for the parents.

3 MINNESOTA STATUTE 125A.03 SPECIAL INSTRUCTION FOR CHILDREN WITH A DISABILITY. “Notwithstanding any age limits in laws to the contrary, special instruction and services must be provided from birth until July 1 after the child with a disability becomes 21 years old but shall not extend beyond secondary school or its equivalent, except as provided in section 124D.68, subdivision 2.”