

# 7 Tips for Advocating for Children with Disabilities and Chronic Illnesses

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**V**olunteer advocates and care providers frequently have questions about how best to advocate for children with disabilities or chronic illness. Working with children who have many service providers and multiple needs may be daunting at times. Here are a few tips to best assess and advocate for the service needs of these children.

## 1. Familiarize yourself with the child's diagnosis:

It is important for key people involved in a child's life to have a basic understanding about the nature, diagnosis, cause and prevention of a disability or chronic illness affecting the child. With a basic understanding of the diagnosis, you will be better prepared to advocate for services, technology, medical care and education needs. Learn as much as you can about the diagnosis and how it specifically affects the child you advocate for. You can find helpful national organizations working on many diagnoses by doing a simple web search.

## 2. Watch for physical and behavioral changes:

Such changes can help you gauge how the child is adapting to a new situation. Ask the caregiver (or an older child himself) about disturbances of eating or sleeping. Physical symptoms such as frequent vomiting, diarrhea and skin rashes clearly call for a doctor's attention. But also watch for confusion or fear produced by unfamiliar events and situations. Problems with daily routine

can be a red flag that a child needs help. Watch for behavioral changes such as hiding, biting or frequent crying. Is this a sign that the child is unable to communicate needs and feelings? Try to find out whether the child has a favorite comfort item and when it is needed.

## 3. Seek out the opinions of those who know the child best:

You may not understand or be able to communicate with the child you are representing. In these cases, it is best to talk to the people who have known this child the longest. It may be a relative, a teacher or a school social worker who can explain to you how the child reacts in various situations. Ask them what can be expected and what would be signs for concern.

## 4. Educate yourself about local resources as well as your child's team of service providers:

Make sure to familiarize yourself with what is available in your community to meet the child's needs. The child you are representing may already have a capable team of service providers. Examples of providers are counseling/psychological service providers, early intervention providers, general and special education teachers, occupational therapists, physical therapists, speech and language pathologists, case managers, social workers, doctors, nurses and nursing assistants.

## 5. Know the child's education rights:

The Education for All Handicapped Children Act went into effect in 1978 and was replaced by the Individuals with Disabilities Education Act (IDEA) in 1993. The law requires states to provide a free, appropriate education to all children with disabilities regardless of the severity of their disability. Under the law, each child with a disability has an individualized education program that indicates what kinds of special education and related services she will receive. IDEA covers children with disabilities from ages 3 to 21, except in states that do not provide public education for children younger than 5 or older than 18. However, you may find your local school district provides programs for children 3 to 5 even when they are not required by state law to do so.

## 6. Know the role of the care provider:

While there may be other significant needs, the primary needs of a child with a disability are the same as those of all children: love and support. The care provider's goals are to foster independence and to help the child develop a sense of self-worth and personal fulfillment. Through therapy and play, care providers strive to help the child you serve deal with her disability while realizing her full potential. How much independence the child achieves depends, to a great degree, not only on the child's disability but on how responsive the care provider is at each stage.



The author with her two sons, Joshua (left) and Brandon

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**7. Focus on short-term goals:**

All children reach plateaus in their development—times when they seem to stop moving forward or may even take a step back. This can be a particularly difficult time for children with disabilities or a chronic illness. In these situations, advocates do best to measure progress in inches rather than yards. When the child you serve reaches a plateau, it is helpful to look back on how far he has progressed. This may also be a good time to focus on short-term rather than long-term goals—finger-feeding, getting dressed or mastering toilet training rather than general readiness

for kindergarten. When care providers focus their energy on a single, short-term goal, a child with a disability or illness may begin to move forward again. By stopping to observe how the child copes with such challenges, how she adapts to new and greater demands, advocates and care providers can develop realistic expectations for the child.

There is much to consider when advocating for a child with a disability or chronic illness. Breaking down your challenges into manageable tasks can help you develop a strong, workable plan for effective advocacy. 

destructive behavior and had lower rates of depression. The approach holds promise for overcoming the disproportionately negative impacts of foster care on youth of color.

The project in this study was similar to the ways former CASA kids describe how their volunteers helped them. “I have goals,” they say, but they count on practical help from people they trust to support them in achieving their high hopes.

What if we took the senator up on his challenge to “solve big problems”? What if we were to create a practical vision of a nation-community working together to “parent” foster youth into adulthood? 



You are there for a child.

**As a CASA volunteer, you understand more than anyone what it means for children to have advocates in their lives.**

Please consider a gift in your will and help ensure that future generations of children benefit from your legacy. To find out how you can give for the future, please contact us today.

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