

How to Advocate For Kids with Special Needs

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No child comes with an owner's manual on how to raise them. As parents we figure out the curves in the road as we go along.

But when you're raising a child with special needs, there can be many more roadblocks and curves to navigate. Often times you feel as though you are driving blind, doing your best to not drive off the cliff.

I know the challenges, as I'm a mom who is on the road of raising a child with special needs. And while it can be an exhilarating ride, with some incredible successes, it is also a bumpy and rather isolated road.

What has helped me on this journey is connecting with other parents and getting advice from others who have gone before. I've learned I don't always need to go this alone, but rather there are others who can shine a light on some of the upcoming hazards in the road or show me how to navigate a certain obstacle.

Here's some advice (parent to parent) to help you on your journey that I learned while writing *Your Child's Voice, A Caregiver's Guide to Advocating for Kids with Special Needs, Disabilities or Others Who May Fall through the Cracks*.

Find Your Team Captain

Who is the ONE person who will be the lead on your child's care? This is the person who will refer to and review all the assessments and tests, look for any red flags, and, ideally, help you advocate for your child. Often the team captain is a pediatrician, specialist or family doctor, depending on your child's medical condition(s). This person is looking at the holistic needs of your child versus focusing on one element of care.

Understand (And Embrace) The Labels

This is the toughest pill for many parents to swallow—having labels put on your child. I spent a lot of time fighting against labels. That is until I learned how the labels could help my child. Many labels are associated with funding, therapy and a community of support. So no label means no support. You need to understand the label or labels your child has, what it means to them specifically and what support is available for each label.

Kids with special needs often have more than one label. An autistic child may have a speech delay requiring speech therapy, a behavioral issue needing the support of an educational assistant (EA) as well as motor issues involving occupational and/or physical therapy. And guess what? Each of these therapies involves a separate assessment and diagnosis, which is in addition to the main autism diagnosis.

Join a Community

There is power in connecting with other parents and caregivers who are also raising kids with special needs. If you live in a large city, you may have parent groups related to your child's specific condition. For those living in smaller communities, find other parents who have kids with special needs. I promise you they are encountering many similar obstacles (and have likely seen some of the same healthcare professionals as your child).

You can also reach out online. I've joined a number of Facebook groups related to my son's condition where I can ask questions and get support from parents who are on a comparable journey—some further down the road than me. Other times I just read the posts, comforted by the fact I'm not alone.

Know your limitations

We all have days when we feel we can conquer the world. Then there are days when all we want to do is retreat to our bed with the covers over our head as we have a good cry. Yes I have been there. More often than I care to remember.

And guess what? That's okay. We can't always be charging into battle. Sometimes the battle wears us down and we need time to recover.

You have an important role to play in raising your child. Some days you need to focus all your energy on that role. Give yourself permission to take life day by day and sit out the occasional battle. Don't worry—there will be another opportunity to advocate for your child.

Finally, please know you are not alone. Although we may be travelling on different roads, there are many of us out here who are also on the journey of raising a child with special needs. We feel your pain, frustrations and celebrate your child's successes. You can do this!

If you want to learn more about how to advocate for kids with special needs, check out my book *Your Child's Voice, A Caregiver's Guide to Advocating for Kids with Special Needs, Disabilities or Others Who May Fall through the Cracks*.

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