

7 ways to better manage your child's Autism and ADHD care



7 Ways to Better Manage Your Child's Autism and ADHD Care

Let's face it – our children with autism and attention deficit hyperactivity disorder (ADHD) require a lot of care and services. Even if you have a case manager helping you through your health plan or Medicaid autism waiver, ultimately you act as your child's case manager overall. You are having to deal with doctors, specialists, school services, childcare and more. So how can you more effectively manage it all? Here are seven tips to help you.

1. Get organized!

It's hard to keep track of everything if you don't know where it is. That's why you need a central location for all papers, notes and anything else pertaining to your child's care. In our modern world, that most likely means one place for hard copies of paperwork and another central location for digital documents. For instance, have one drawer dedicated (or partly dedicated) to holding all your paper files. Have it located in an easily accessible place, whether that is in your kitchen, home office or other room. Have subfolders labeled for school, medical care, autism waiver, etc. On your computer, have a subfolder dedicated to housing the documents for your child.

In addition, find a good calendar to use to keep track of appointments and activities for your child. This could be a digital calendar such as Google Calendar, iCalendar for iPhones or a family calendar such as Cozi. You also could use a wall calendar in your home or even a pocket calendar that you carry with you. Choose whichever one you will use, then put it to good use.

With all the calls we put into providers and to the school for our kids, we usually have follow-up calls or emails that must be completed. Schedule those on your calendar!

If you don't need them, you can delete them if the provider, teacher or whomever follows up with you before then. Otherwise, you will have a reminder on your next step to keep your child's care on track.

2. Develop a good relationship with your child's primary care doctor

Your child's primary care doctor – whether a pediatrician or family practice physician – is a wealth of information and key part of your child's care. Therefore, it is so important that you find one you can trust and develop a good relationship with him or her. Your child's doctor can refer you to specialists needed such as behavior therapists, occupational therapists, psychiatrists, centers for applied behavioral analysis and more. The doctor also will oversee your child's general health care.

If your child has an autism waiver and you also have private health insurance through an employer or through the Affordable Care Act (ACA), your child's doctor may not accept services through Medicaid. That is okay. When you need services through the autism waiver, rely on your child's case manager for those, however, it's good to keep your child's doctor up to date on what services and the provider your child is receiving through the waiver (e.g., patient assistance/care, recreational therapy, behavior therapy, music therapy, or other services). This allows the doctor to have a good overview of all the care your child is receiving, so they can provide the best advice when it comes to the care needed through network providers from your health insurance.

3. Document everything

With so much care being provided, it's important that you have the documentation for everything. That's where your organization steps come into play! Make sure you receive and save the documentation from your child's case conference for their individualized education plan at school, quarterly and annual meeting reports from your child's case manager for the autism waiver, vaccination records, school progress reports and more!

You will be surprised how often you will need to refer back to these documents. We can't remember everything, and sometimes you need to access these for new services needed.

In addition, make sure you log your child's milestones. Not only is this a great way to document their development, you also have a way to celebrate their victories along your journey!

4. Take a holistic approach

Your child's care isn't just the medical services they receive. You should take a holistic approach to the care your child needs, including those from their school, childcare and even playdates.

By taking a holistic approach to caring for your child, you will be ensuring they receive everything they need. For instance, your child is eligible for many services through the school system such as speech therapy (for social skills training) and classroom support. Also, you have a lot to consider for childcare, whether it's respite through an autism waiver or other government provided program, daycare, before/after school program or a specialized babysitter who is trained to work with kids on the spectrum.

Your child also may participate in other types of services or programs such as Special Olympics teams, equestrian autism programs, music therapy or musical instrument lessons, social skills groups or supervised playdates with other kids on the spectrum. Make sure you include these as they help your child's development.

5. Choose your child's providers wisely

There is nothing more frustrating than realizing you've chosen a provider who is not a good fit for your child. And there is such joy in knowing a provider is the perfect one for

your child. That is why it's so important that you research your provider options and meet them before selecting your child's providers.

In some cases, you may have a limited selection of providers due to in-network restrictions for your health plan or the autism waiver participants, or just the limited number of providers in your area. However, if there are several available, do your homework. Search for them on the Internet to see what recommendations or "grades" have been given to them. Ask friends and your child's primary care doctor for recommendations. Spread your reach and ask your friends on your social media channels for recommendations.

Choosing your child's providers wisely can ease your stress and also ensure your child is receiving the best care available.

6. Manage your finances well

With all the care and services we need to obtain for our children, we face higher costs for those. Those could include higher health care insurance premiums, deductibles and coinsurance; out-of-pocket costs for services that are not covered by health insurance or government program; special food if your child needs to eat a gluten-free diet; higher childcare expenses for specialists who know how to care for children on the spectrum; and other specialized items and activities that are needed.

Therefore, it's important that you manage your finances effectively. You need a monthly budget where you not only plan for the month's expenses, but you can track your daily output to keep on top of where your money is going. It's important to ensure you have your basic financial foundation taken care of such as required insurance (e.g., health, life, disability, automobile and home), emergency fund and retirement savings. You need financial advice about whether you need an ABLE account or special needs trust for your child. Is your child moderate to high functioning? Then what about saving in a 529 plan for college or vocational education expenses after high school.

Do you need to reduce your daily expenses, so you have the funds needed to pay for care? Search for frugal living e-books and websites to gather ideas for what will work for your family. Also, look for financial support available through local autism support groups and other organizations. Help is available if you look for it.

7. Know when to move on from a provider

Sometimes, you need to walk away from a provider. We can think we've made a good choice, but over time, things can change, or the relationship may take a step in a new direction. It could be that your child has advanced in that area, and they no longer need that service. Maybe the service you were receiving decreases in quality over time. The chemistry between your child and their provider may change, and it's no longer in your child's best interest to receive the care or service from that provider anymore.

Whatever the reason, don't stay in a situation that needs to change any longer than you must. It's understandable that you may need a little time to find a new provider, so you will need to continue that service with the current provider until a new one can be found. It can be frustrating and time consuming to look for a new provider, but you will regret it if you put off doing the tasks that need to be done to move forward.

Remember that you know your child best, and you know what is best for your child. Even though it's a lot of work, managing your child's care effectively is worth it. It will result in better outcomes for your child to help them succeed in life and help you and your family today.