

Importance of Respite for Parents of Children on the Spectrum

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respite

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Imagine holding your arms out on each side and placing a small book in each hand to represent a stressor. If you keep adding books without taking time to rest, your arms will eventually give out or “breakdown.” This metaphor for stress illustrates how important it is for you to take some time for yourself and alleviate the weight of the books, or stressors, so you are better able to handle the things that cause anxiety and worry. Parents of children on the autism spectrum can often feel overwhelmed by their added responsibilities in caring for their child which can lead to intense stress. The stressors of raising a family affected by disability can cause chronic health problems for parents both physically and mentally. Mothers caring for children with disabilities are more likely to spend more hours providing care, be more tired, and encounter a stressful event than mothers of children who do not have disabilities.¹ When these stressors become overbearing, you should seek out respite care as a method of recharging your batteries. This article hopes to demonstrate the importance of respite care for parents of children with disabilities and discuss the different ways to obtain respite care.

The Importance of Respite

We don't have to tell you that being a parent is a full time job from the moment your child enters this world. Your life's mission is transformed in an instant into caring for your little bundle of joy, which can quickly turn into a hectic and tumultuous assignment. There are so many obligations and “what ifs” that worry parents that it is no wonder that individuals can let the pressures and stress get to them now and again. Take these worries and stressors and then amplify them by adding a disability that prohibits their child from effective communication or engaging in typical activities. Then add the uncertainties of how to financially provide treatments, the time constraints that accompany treatment, ensuring their child receives a proper education through an [IEP plan](#), and preparing for a cloudier future than then they originally planned. All of this can cause your stress levels to reach their maximum capacity.

Respite activities reduce the stress and pressures of everyday life by giving you a deserved break. Not only is it good for your blood pressure, but it can help improve the often strained relationship between parents and their children. As a caregiver to someone with a disability, you deserve a period of rest and relaxation where you can focus on your needs instead of the needs of everyone that you care for. Well, that is the essence of respite care, which can be delivered in a dozen different ways from simply hiring a qualified babysitter to enrolling your child into a camp. There are two different models for respite: In-Home Model or Out-of-Home Model for respite, and each model has its own pros and cons:²

- **In-Home Model:**

- The child receiving the care may be most comfortable in the home setting and does not have to adjust to a new environment. This may be especially important for children on the spectrum who tend to demonstrate a strong proclivity for routine
- Parents may be more comfortable knowing the child doesn't have to leave the home
- Cost tends to be lower than the Out-of-Home Model
- Your home may be equipped for any special needs the child may have
- No transportation barriers

- **Out-of-Home Model:**

- These respite types generally occur for a part of day, overnight, or even weeks and can include camps, residencies, and Residentiality, which consist of participating hotels providing a room for your family and dinner while a local respite program takes care of your child
- Transportation may be required and special equipment may need to be moved
- The individual may not embrace the new environment, causing difficulties for the caregiver
- Services may be more restrictive than an in-home respite visit

The method or model you choose is inconsequential as long as you allow yourself the liberty of respite. The idea of respite is to take some time for yourself, so that when you are done you come back relaxed, refreshed, and ready to continue your parental journey.³ In fact, respite may contribute to you having a stronger marriage and becoming a better overall caregiver. According to the Oklahoma Respite Resource Network, more than one-third of family caregivers surveyed in that state had been or are separated or divorced. However, of those still wed, 79.5% said respite contributed to the stability of their marriage, and 98% of those surveyed stated respite made them a better caregiver.⁴ The simplest sacrifice, like taking care of your child so that your significant other can have a relaxing bath or a night out with the guys, can be considered respite and a good way to strengthen your marriage.

Attaining Respite Care

Respite services are federally funded as part of Home and Community-Based Services Waivers, and each state develops its own waiver income, age and disability eligibility criteria. Individuals who qualify for Medicaid in their state are eligible for these services.⁵ Find out if you qualify for your state's Medicaid here. Aside from paying for respite services yourself, there is one other option and that is to contact your local Department of Social Services.⁶ ARCH National Respite Network has a state-by-state locator of respite services and agencies nationwide. The site also includes an interactive map that allows users to search for funding for respite care dependent upon the individual receiving the care. The numerous types of respite options make it so families don't have to go through official channels. You could also find a qualified respite provider on Craigslist or search National Autism Network's provider directory for respite services or the events calendar for respite events geared towards parents of children on the spectrum. Regardless of the avenue with which you find your provider, there are a couple steps to take and things to consider before hiring independent professionals to provide services:⁷

- **Interview:** Conduct an interview with potential respite providers over the phone to detail the specific tasks they will be required to complete, the skill level of the individual, and scheduling/time involved. It is wise to conduct a personal interview upon arrival to discuss specifics.
- **Experience:** Make sure the individual is a professional. Discuss compensation prior to hiring and do not pay in advance of services rendered. Ensure the individual has prior experience working with children on the autism spectrum

- **References:** Request work and personal references, and make sure to verify them for accuracy. You may also consider running a background check, which is easier and less expensive than ever before.
- **Contract:** Develop a contract that details compensation, services to be provided, and scheduling in the event that conflict arises.

Independent services are generally less expensive than going through an agency, but agencies take care of the pre-screening duties, handle payroll, can provide substitutes in the event of sickness or personal obligations, and you have specific avenues of recourse for complaints or, if necessary, arbitration. For list of important questions to ask when choosing a respite program, click [here](#).

Conclusion

As a parent, when you first discover that your child has a disability, you vow to do anything in your power to make sure they have every advantage possible in life. However, sometimes the best way to fulfill that pledge is to take a step back from it all and allow some time for yourself to break from your parental obligations. By foregoing respite, you take the risk that your stressors could manifest themselves in such a way that is damaging to you or your child's overall well-being. Do not let this happen. Respite care can do wonders for your overall well-being. Being a caregiver and a parent essentially two full-time jobs in one, and you **should not** feel guilty about taking time away.

The [ARCH National Respite Network and Resource Center](#) is a comprehensive resource for those in search of respite care with links to the ABCs of Respite, state-by-state respite service locators, webinars, resource guides, training resources, and a Legislative Action Center.

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