



# Complex Child E-Magazine

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## The Importance of Respite by Susan Agrawal

I have a new baby who is typically developing, and recently came across this common bit of advice for coping with a cranky baby:

Build a support network--your pediatrician, your spouse, your mother, other parents--anyone you can turn to when the crying gets too overwhelming. Sometimes just talking to someone about how stressed you feel can make all the difference. Other times, you may need to get away from your baby for a short break; find a trusted caretaker who can pitch in when you need to relax.<sup>1</sup>

This is important advice for anyone, but reading it made me reflect that things are just not that easy when you have a child with exceptional needs or complex medical issues. You can't just hand over a child with a feeding tube or trach to your sister or your neighbor. Your mom--and even your spouse--may have no idea how to handle your child with autism and his difficult behaviors.

But parents of children with special needs, especially children with a particularly high level of required care, need a break. Many of us are chronically sleep-deprived, overwhelmed, and exhausted. Our other children act out from lack of attention, our bodies suffer from over-exertion, and our spouses feel neglected. This is not healthy for us, our families, and especially not healthy for the child with special needs.

Respite, or respite nursing care when applicable, is the solution to this problem. But as many families have discovered, the solution is not always easy to achieve.

### The Problems

**Locating respite services is very difficult.** Currently, respite care is provided through a very patchwork system. In some states, respite is only available through Medicaid waiver programs, many of which have long waiting lists. In other locales, other programs, such as early intervention, public programs for children with developmental disabilities, and private charities, may provide respite services. In rare instances, insurance may cover respite nursing for children who are very complex.

When my daughter was an infant, I remember spending hours trying to identify agencies that were currently offering respite services. I then had to spend hours filling out separate

forms for each agency. The process was daunting and overwhelming on top of the many other issues I dealt with on a daily basis, such as a child who screamed nonstop, threw up constantly, needed tube feedings, and had six therapy sessions a week. I actually was forced to set the entire process aside for several months because I simply could not get it done, and the process itself was stressing me out more than daily life.

This fragmented approach to providing respite is far too difficult and needs to be simplified, especially for parents who are as overwhelmed and exhausted as most of us are.

**Many programs have waiting lists or strict requirements for acceptance.** I remember being told to put my child's name on the waiting list for respite through Jewish Children's Bureau as soon as possible, because it took years to get a provider. At age three, my child was still number 50 on the waiting list. By that point, she no longer qualified for the program because she was too medically complex, and her name was removed from the list.

My experience is quite common. Waiting lists, especially if services are provided through Medicaid waiver programs, can be as long as ten or more years. Is it really acceptable to expect a family to wait ten years before they can have one date night?

Different programs have varying criteria for acceptance. Many programs will not take children with any level of medical complexity. Other programs exclude children with moderately complex needs, and only accept those who are extremely fragile or complicated, such as children with trachs and vents. I know so many families, including my own when my daughter was young and not as sick, who are caught between these two extremes. Their children are too complex to qualify for most basic respite programs, and not complex enough to qualify for nursing care programs.

Respite needs to be made available to all families of children with special needs, regardless of level of medical complexity. Waiting lists need to be eliminated or shortened to days or months. Many families need that break now! I remember trying to explain to my insurance company that paying for a few hours of respite nursing would be a whole lot cheaper than paying for a month-long stay in a mental hospital when an overwhelmed mom finally breaks down.

**Respite workers are in short supply.** My daughter is approved for approximately 300 hours of respite per year. Thus far, we have never used any of it. Her respite needs to be provided by a skilled nurse, and we cannot even fill her regular school-day and night nursing shifts, let alone find someone to work evenings or weekends so we can get out. As a result, my husband and I have only been able to have a "date night" on average once per year. Just trying to coordinate the whole process--getting a nurse in place and hiring a babysitter for the other children--is overwhelming. And by the time we actually get it set up, we're usually too exhausted to stay out for more than a few hours.

Our experience is not uncommon. Even when approved, respite workers can be very hard to find, especially for children with more complex needs. It takes an average of four shifts before a nurse is comfortable caring for my daughter without assistance, meaning that anyone providing respite has to be one of her regular nurses. Approving respite is useless if it cannot actually be provided or used.

**Respite workers are poorly paid and unqualified.** I remember being shocked to find out that most respite providers receive \$8-9 per hour to provide care. Considering we pay our babysitter \$10 an hour, which is standard in our locale, I could not believe that a respite care provider would actually receive less. Why on earth would they be paid less to do a much more difficult job? It made no sense at all.

Consequently, many of the respite providers who were sent out to meet us were not what I would consider to be qualified or even acceptable. In our case, the first person sent out was a woman who showed up two hours late, reeked of cigarette smoke, and had her niece and son in tow. I would not have left my child with her for even a second. Abuse is rampant, unfortunately, and it is hard to trust some of these individuals.

Many respite workers receive little or no training. While there are some programs that are exceptional and provide CPR training and courses on behavior and caregiving skills, many agencies just send out anyone who has completed high school, has a car, and can pass a basic background check. These individuals may not have the skills or even the intellectual level to handle the situation, especially for children with high needs.

When my daughter was a baby and less sick, we ended up going with a volunteer respite agency that really supported its volunteers and made a strong effort to provide them with the training they needed. But these groups are rare, and most families do not receive this level of care and dedication, unfortunately.

**Respite workers are not permitted to perform medical procedures.** Many families qualify for respite services but end up not using them because the respite care provider is not legally permitted to perform even the simplest medical procedure, such as giving a tube feeding or administering a medication. Our agency had such a restriction, which meant that we could only sneak out for the two hours between all of my daughter's medical procedures. We often barely had time to eat dinner, and were hurried the entire time.

Respite workers must be able to meet all of a child's needs in order for respite to be effective. Otherwise, respite becomes impossible to use.

## Solutions

The following are my suggestions for making respite available to all families with children who have special needs.

- Private insurance and Medicaid should cover four hours of respite per week for any child with a qualifying diagnosis, such as cerebral palsy, autism, or cognitive impairment. This will be cost-effective in the long run, as providing a break to caregivers is likely to improve their health and their ability to care for their child appropriately.
- Respite workers should be trained adequately, including full CPR training and coursework on child development, behavior, and management strategies.
- Respite workers should be paid at least \$2 more than the typical wage paid to babysitters in the area, or a minimum of \$10 per hour. Higher pay may help to address the short supply of respite providers and help to identify more qualified individuals. Respite nurses should be paid a salary commensurate to their experience.
- Respite workers should be able to meet all of a child's needs. Providers for children with significant behavioral issues need training in behavioral strategies. Children who require medication or tube feedings should have a home health aide or equivalent as their respite providers. A trained nurse should care for children who require more intensive medical procedures.

Respite is an absolute necessity for families and should be provided to all families who wish to use it. Simply put, respite saves families and is beneficial to every family member.

We have had only three nights out in the past three years. That is simply unacceptable, and I can tell you I struggle with fatigue and burn-out regularly. The average American family, on the other hand, spends at least one night out per month, and they do not have to deal with half the things that we do as parents of children with special needs. We need to make respite a greater priority in our health care system, for our own health and for the health of our children.

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<sup>1</sup> [http://www.babycenter.com/404\\_my-babys-constant-crying-is-very-stressful-how-can-i-cope\\_11754.bc](http://www.babycenter.com/404_my-babys-constant-crying-is-very-stressful-how-can-i-cope_11754.bc)