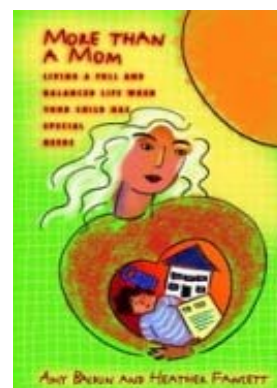


More Than A Mom: Living a Full And Balanced Life When Your Child Has Special Needs

by Amy Baskin and Heather Fawcett

This book is full of practical advice, strategies and reassurance. Read important excerpts from More Than a Mom's chapter on *Finding the Help You Need*.

"We moms are often reluctant to ask for help ... Yet, using services doesn't mean that you're not capable. By increasing your child's support system and people who know and care for her, you help her to be as independent as possible in the future. Plus, you help to ensure that the rest of your family stays healthy and happy."



Access Respite or Short-Term Care to Accomplish Tasks or to Take a Break

Years ago, respite (a break from caregiving) was provided by extended family members who lived in the same house or close by. Grandmas, sisters, and cousins actively cared for the kids so parents could get a much-needed break. Now, family members often live far away or work full-time themselves, making it difficult for them to pitch in.

Formal respite services began to develop in the 1960's, when governments began closing institutions and moving individuals with special needs back to their communities, often back in with their families. The aim was to give families relief from constant caregiving, especially when informal supports weren't there. Today, the need is greater than ever.

Respite can be provided in many forms and funded in various ways. Respite can mean having someone come into your home to look after your child or having your child stay overnight at someone else's home. It can mean sending your child to enjoy activities in the community with a support worker, while you enjoy time to yourself. Respite can be provided during the day or overnight, short-term (a few hours) or for a few weeks (while your family goes on a vacation, for example).

Monica sends her twenty-four-year-old daughter with Angelman syndrome to overnight respite camp for three weeks during the summer and seven weekends throughout the rest of the year. "Camps are wonderful respites!" We go out to dinner with friends, go to the movies, and go on vacation ourselves for a week when she's at summer camp."

What often confuses parents is the fact that there's no one consistent approach to respite care. The services provided, the organizations that provide them, and the families that qualify can vary tremendously, depending on where you live. Respite may be funded totally or partially by the government or a community organization. You may pay part of the cost on a sliding scale according to income, or you may pay the full price of the service yourself. In some cases, private insurance may partially cover it.

As a parent of a child with special needs, you might be able to receive an annual respite stipend from your state or province, or receive a voucher allowing you to purchase respite services from a community provider. Or, in some states, you may receive respite in the form of a government-sponsored program such as a Medicaid waiver. Sometimes, respite is sponsored by a hospital, community agency, or service club (e.g., Rotary club, Easter Seals). In addition, respite programs may be offered by a church, school, or special needs association, or by a volunteer host family in their own home. A social service agency may even partner with a private business such as a hotel. While your child is cared for at home, you and the rest of your family enjoy a meal, swim, and overnight stay at the hotel.

Respite – Go For It

Despite the challenges of finding and funding respite care, it's well worth pursuing. Respite time enables you to do errands, relax, or enjoy time with your partner or other family members. Building a relationship with a provider means you have a reliable caregiver for your child if there is a family emergency. Children enjoy trying new activities and making social contacts outside of family, especially as they get older. Amy's daughter, Talia, for example goes out with respite workers in the community, and enjoys swimming, indoor rock climbing, library visits, hiking, skating, movies, and more with them. These outings expand her social world and give her a chance to gain independence from family members. Some day your child may live on her own, in a group home, or other supported care. Out-of-home respite care gives your child, teen, or adult a chance to test the experience of living outside the family home.

Ask other families of children with similar care need to recommend respite staff or programs they have used. When meeting with respite agencies, ask about the qualifications of staff and whether you can choose the respite worker. For care outside of your home (such as respite spots in a group home), ask for details about the daily routine, meals, recreational activities, and emergency procedures. Also, ask about the other children who might be in respite care at the same time. Are their needs and diagnoses similar to our child's? What is the ratio of staff members to children? Does the program provide transportation? How far in advance can

you book respite? And do they care for siblings? In addition, see the questions for child care providers in Chapter 20. If you are interviewing a provider to come into your home, use the sample child care interview in Appendix 5 as a starting point. Most respite programs have a detailed manual for parents and families that contains answers to many of your questions—so ask to see a copy.

We moms are often reluctant to ask for help, since we're so used to being independent. Yet, using services doesn't mean that you're not capable. By increasing your child's support system and people who know and care for her, you help her to be as independent as possible in the future. Plus, you help to ensure that the rest of your family stays healthy and happy.

Where to Find Respite Care

Access respite services through a Medicaid waiver or other government program, or through community agencies.

The nonprofit ARCH National Respite Network run by the Chapel Hill Training–Outreach Project has an online locator service that helps parents find respite agencies across North America (see Resources). The site lists for-profit home care providers, as well as nonprofit agencies, so be sure to get thorough information about the different options. If respite is unavailable in your area, approach your community for help. One mother created a popular respite night through her church. Start your search by talking with your local contacts (other parents, your case manager, school teachers, doctors, therapists, and children's treatment centers). ARCH National Respite Network also has information from their website to help you start your own group.

Find Out about Your Community Resources

“I use the Boys and Girls Club three hours a week and use a Community Centre program on Saturdays for four hours,” says Daphna, mother of a child with autism. “I have finally found a 1:1 worker who works five hours per week. I have also arranged with an agency for every-other-weekend of out-of-home respite.”

Some moms like Daphna take full advantage of what their community offers. Your child may participate in a free, agency-sponsored program. Or you can use respite dollars to cover fees for community programs or to hire personal care attendants or one-on-one workers to enable your child to attend. Private insurance sometimes covers the cost of therapeutic

community programs such as speech, and language or physical therapy. As always, ask other parents, professionals, and agencies you deal with for their suggestions. Some examples of programs include:

- Volunteer and friendship programs that provide social interaction for your child and free time for you. Best Buddies, for example, pairs youth and adults with intellectual disabilities with secondary school, college/university, or work peers.
- Specialized programs for people with disabilities provided by agencies or nonprofit-groups. Examples include Special Olympics (sports and friendship), social skills groups, and specialized cooking classes. Often, volunteers pair up with professionals such as speech, occupational, or physical therapists, social workers, etc., to provide the service.
- Day programs, after-school programs, or work programs. Special job coaching agencies may help youth and adults find work or volunteer opportunities in the community.
- Community recreation groups like those run by the local YMCA, recreation and parks department, or the Boys and Girls Clubs. These may help with life skills and integration into regular programs. Often these groups provide volunteer one-to-one support for children with special needs.
- Churches, synagogues, and other places of worship often provide support for children and adults with special needs who want to participate in regular groups. Some offer specialized religious instruction or recreation for people with special needs.
- Commercial recreational programs (such as dance, karate, basketball, music) sometimes offer specialized classes for children with special needs. Others help to include all children in their programs by providing volunteers for extra support.

Digging Deep – Have You Tried...?

If you've been unsuccessful at getting funding through public assistance or private insurance try these sources:

- Ask other parents, local disability organizations, and social service agencies (and professionals) whether they know of any other funds earmarked for families of children with disabilities.
- Your local Independent Living Center (ILC) may have funding for home modifications or other equipment.
- Research large disability organizations such as United Cerebral Palsy, the Arc of the United States or Muscular Dystrophy; besides information, groups sometimes provide services like respite care or fund disability scholarships or equipment loans.
- Assistive technology manufacturers may offer guaranteed loans or “try before you buy” programs for equipment or technology. Also, they often have information on other funding sources.
- Forty Alliance for Technology Access centers across the U.S. offer software lending libraries, toy libraries, product and vendor information, access to computer labs, training, free loan of refurbished computer equipment, and more. Some services may require fees.
- Service groups such as Easter Seals, Rotary Club, and March of Dimes sometimes have equipment loan, respite, vocational, camps, or other helpful programs. Other groups such as Kiwanis, Knights of Columbus, Masons, Optimist, Sertoma, and the Lions often raise money for individual needs in their community. Since many groups only focus on one type of disability, contact them individually by visiting their websites or finding their local contact in your community phone book.
- Children’s foundations may help with specific circumstances, e.g., the Make a Wish Foundation or the Starlight Starbright Children’s Foundation may help a child with chronic, serious, or life-threatening disease fulfill a life dream (such as visiting Disneyworld). Starlight may also fund a computer for a child who is hospitalized for a long time. The Disabled Children’s Relief Fund helps children with inadequate insurance pay for wheelchairs, orthopedic braces, walkers, lifts, hearing aids, eyeglasses, medical equipment, physical therapy, and surgery.
- Look for disability-related, charity, and foundation directories at your local library. Most major libraries have The Foundation Directory (Foundation Center, New York). Each provides eligibility criteria, the application process, and deadlines for each foundation. Or for a fee, access them online (The Foundation Center provides some basic information for free.)
- Universities, colleges, and other post-secondary institutions often offer disability-related scholarships. Check with the Financial Aid office of the post-secondary

institution. Federal and state governments may provide aid under some circumstances. Consult your Department or Ministry Education.

- Check with religious charities, churches, synagogues, schools, employers, chamber of commerce, hospitals, labor unions, sororities and fraternities, or veteran groups, to find out what type of funding they may have available.
- For added clout, join with other families who have similar funding needs. It's easier to ask for money that will benefit an entire group of children, rather than just your family. For example, you can ask a company to fund extra aides for kids with muscular dystrophy to attend summer camp in your community.

With networking, research, and a good deal of persistence, you can find services, funding, and supports to enhance your child's day-to-day life, as well as your own and your families.

*Heather and Amy give workshops and keynotes based on *More Than a Mom* for special needs groups and conferences. For information see www.morethanamom.net. Also, read Amy's special needs parenting blog for *Today's Parent Magazine* at <http://blogs.todaysparent.com/category/specialneeds>*