Stress is an ever-present reality in families with autism. It colors the way we view the world. If internal stresses on the family, marriage, finances, plus safety issues do not get to you, there are always external stresses that can. Dealing with extended family, educators and medical professionals usually present additional opportunities for stress to take hold.

I have gained much wisdom over the years by trial and error. Hopefully, I can help you avoid a bit of trial and error and encourage you to find ways to help relieve the stress that you and your family experience.

**INTERNAL STRESSORS ON THE FAMILY**

The internal stresses of autism on the family can range from practical problems of a child not sleeping, to emotional problems of guilt and marital strife. Many practical solutions and tips for these issues are found in my booklet, *The Child with Autism at Home* (you will find information about my booklets at the article’s conclusion). I am only dealing with the emotional issues for this article. Resolving them can make the practical problems easier to bear.

**I. Stresses on Parents**

Guilt is one of the greatest internal stressors. Most of us feel that somehow we must be responsible for our child’s autism—surely we caused it somehow. I once met a mother who blamed herself because she bottle-fed her child. I told her I had breast-fed my children for over a year, and I was sure that I had had toxic milk! In an odd way, we would feel better if it was somehow under our control, but it is not. Autism is a worldwide phenomenon. Lose the guilt and realize the only thing you can really control is how you interact with your child and the people around you.

Dread is another major stressor. Children with autism do not have an appropriate sense of fear. A bunny with wiggling ears may send them shrieking in terror, but they think nothing of trying to climb off a third-floor balcony.
A parent constantly looks for ways to protect a child with autism from him or herself. You may feel like your child’s life depends upon your hyper-vigilance. I have concluded that the three times I found Nicky with his leg out the window were pure grace. I took responsibility for fixing the problem with window alarms, but my son’s life was and is in the hands of God. I have to trust that my son will continue to be safe. I will do my part, but I am not alone.

Guilt and fear are your enemies. No one can live with them for long. Your child’s autism is not your fault, nor can you prevent every accident. You can only do your part and make peace with what you can’t do.

II. Stresses on Siblings

Siblings of the autistic child are often deeply affected by the family dynamics. Some try to be extra good so that they do not add stress to the home. They can assume a parent-like role to both their sibling and parents. Such children often deny very real feelings of loss when their sibling destroys their projects and toys. Parents can add to this burden by not allowing the siblings to display the normal give-and-take with the child with autism. To keep peace in the household, the typical child is asked to make major behavior modifications to avoid upsetting the child with autism. I applaud their maturity and sensitivity, but as parents we need to relieve their stresses as much as possible.

Siblings can be helped in many ways. Carve out special time with them and provide a locked closet or chest where they can keep their special things. Every child fights with his or her sibling. Do not use guilt to stop it. Find out what they are upset about and find a way to positively address their concerns. Even if you can’t see a way out of the situation, it means a lot to simply be heard. Providing sympathy can make the inevitable easier to bear.

III. Stresses on the Marriage

Some couples are blessed with large supportive families that help out with the children and allow parents to have individual time apart or couple time. Many, however, do not fall into that category. Our parents may be too elderly to meet the physical demands of a child with autism, or simply too far away. For many of us, our primary source of support is our spouse—but this adds considerably to the stress within the marriage. Like two drunkards, the exhausted couple leans on each other as they stagger forward.

The years before the child goes to school are particularly difficult on a stay-at-home mother. The only time you can have a break is when your husband returns home from work—but that is his only time off, too. Everything from haircuts to shopping for groceries has to be negotiated and someone always has to be home with the kids.

The stress of living with a child with autism can be overwhelming at times, too. It is easy to feel like others are not doing their part. The truth is that even if everyone did their part to your satisfaction, it would still be overwhelming. Spouses need to stop blaming each other for what they are not doing, and start thanking each other for what they are doing—going to work, putting food on the table, feeding and dressing the children. You might think that you shouldn’t have to thank somebody for just doing his or her job, but being appreciated buoys the heart and heals many wounds. People who feel unappreciated can get resentful, and that creates a toxic environment. The couple becomes physically and emotionally distant at best, openly hostile at worst.

And what about intimacy? Don’t laugh—you remember what it is. Unfortunately, stress and intimacy are incompatible for both men and women. So, you need to make special efforts to relax; otherwise, it will feel like one more demand upon an emotionally tapped out person. Intimacy can recharge your emotional batteries and strengthen the bonds of marriage.

I believe it is crucial to the health of the marriage that each spouse has one night each week that they can absolutely count on to get out of the house. Money spent on a babysitter is money well spent, if you have it to spend. Other options are to barter, or to ask for assistance from a local church or synagogue. Time spent on your marriage will alleviate stress and help the two of you face the situations you encounter daily. You may feel you can’t afford the time for your relationship. The fact is, you can’t afford to ignore it. Making time now will avoid more stress later.
**IV. Financial Stresses**

Autism can place financial strains on families in several different ways. Some families spend fortunes on therapies and treatments for their child. We’ve spent money adapting our house for Nicky and replacing some of the things that he’s broken over the years.

It can seem almost blasphemous to place money concerns above your child’s welfare. You probably feel that if it helps your child, then every penny is worth it. The trouble is that many things don’t work. I have tried some treatments that I am convinced caused my child to regress. Before you spend a lot of money and subject your child to questionable and perhaps dangerous treatments, wait. Ask others who have done it. Watch their child for a few months. Is the child doing better? Could the improvement be the result of some other therapy?

“Stress spending” can sink a financial ship. Some people spend money on clothes or trips, but honestly, most stress spending that I have seen is on the kids. People buy every toy, video, gadget and computer game that they think may interest their child. When the feeling of hopelessness over autism threatens to overwhelm them, they hold it at bay with a new set of toys that might make the difference. Of course, too many choices can overwhelm the child, but as parents we feel the need to do something.

A better solution would be to set up a toy exchange with other parents. If you have toys that your child doesn’t want, exchange it with another parent for a different toy. The toys do not go to waste and your child gets a variety of gadgets to play with. Remembering that money won’t solve all of your child’s problems may be the key to alleviating some of your financial stress.

**EXTERNAL STRESSORS ON THE FAMILY**

The internal stressors may be somewhat under your control, but when it comes to dealing with the outside world, everything is more difficult for parents of autistic children. I could write a book about those stresses and how to deal with them. In fact, I did. *The Child with Autism Goes to Town* is a tips booklet to help families with autism deal with those necessary interactions with society. Those issues are only covered lightly in this article. Instead, I want to focus on how to interact with others to get the physical and emotional support that you and your child need.

**I. Stresses from the Extended Family**

Probably the stress with your extended family began before you ever heard the word “autism.” When it became obvious that the child was having behavior issues, your extended family probably gave plenty of “helpful” advice. And that advice often doesn’t end after the diagnosis. Of course, it helps to remember that those offering the advice truly want to help. They love your child—and you.

Much of the stress of constructive criticism could be alleviated if people would learn to sandwich their advice between genuine compliments. For example, “I do not know how you have the stamina keeping up with that kid night after night. I think if you kept your house warmer, he would sleep better for you. You are such a good mom; you deserve a good night’s sleep.” It is really hard to get offended when someone affirms your worth and dignity while delivering advice.

**II. Stresses with the Medical Community**

When my husband was in medical school in the late 1980s, he was told that autism was so rare that he would probably never encounter a case of it in his lifetime. Pediatricians were not even required to study it. These days, people should not encounter the reluctance to diagnose autism or pervasive developmental disorder (PDD) that those with older children encountered. Nevertheless, getting treatment—not just treatment for autism but treatment for health problems the child cannot describe—is only slowly improving.

I heard a story about a doctor who saw a child with autism brought in for constantly biting his hand. The doctor took the time to look down his throat and saw that it was full of ulcers from acid backwash. A prescription of antacids fixed the problem. Many doctors would have just said that the hand biting was a symptom of autism and prescribed an anti-psychotic. This and other doctors are starting to swap symptoms that autistic children may display when they are ill, so perhaps there is a new day coming for our children in the medical community.

**III. Stresses with Educators**

When it comes to getting appropriate education for their children, some parents literally bet the house. They set up their own in-home programs or private schools, funding it with home-equity loans and fundraisers. They usually end up suing the school district to cover the cost of the program because the district’s program was not appropriate. I honestly do not know how they do it, but I
know I owe them a huge debt of gratitude. One mother in our school district, Jae Davis (see accompanying article by Jae’s husband, Bill), whose son is one year older than my oldest, fought like crazy because there was no autism program in Lancaster County, Pa. She made them pay for her in-home program. The next year, my son Sam entered the first class specially designed for children with autism using ABA. Every year she kept upping the ante on the school district. When she died at age 43, my sons were getting ABA and Verbal Behavior Therapy and her son was finally in our schools. If you know of someone in your community struggling financially to educate their child, go to their fundraisers. It really benefits us all.

On the other hand, please remember, nobody goes into special education because they hate children. They wish more than anybody that they had a bigger budget and more staff to work with—but they are working with budgets determined by elected officials. Autism education reform needs to start in the local, state and federal budgets. Families do not have the political clout or deep pockets of a National Rifle Association or National Organization for Women, but our children only have our voice. Until autism education is properly funded, sharing services, money and staff with others is a reality. Use some of your stress energy to motivate you to be a voice for change.

IV. Take a Break

Get out of the house and away from the kids for a while. Ask family or friends to help. Say, “I really need a break. Is there a time in your schedule when you could give me one?” That changes the question from “can you” to “when can you?” If family and friends cannot help, ask your church or synagogue. Some mental health and mental retardation agencies have funds for family respite and the names of people in the area willing to watch children with special needs. Ask, ask, ask and soon enough you will receive.

Mutually Rewarding Opportunities

I will be offering my tips booklets The Child with Autism Goes to Town, The Child with Autism at Home and my future booklet, The Child with Autism Goes to Florida, through the Autism Society of America. You will get hundreds of practical tips on every area of life with a child with autism, ASA will get needed funds to continue advocating for our children and I will get the funds to keep developing new resources for the family. You can buy them from ASA, or at my Web site www.laboshpublishing.com. Type in “ASA” in the coupon code, and I will send a donation to ASA. Now, go find your joy.

ABOUT THE AUTHOR

Kathy Labosh is the mother of two boys with autism.

She is also the founder of Labosh Publishing in East Petersburg, Penn., which produces tips booklets for families and is developing adapted academic textbooks for the autistic learner. She is the author of two booklets, The Child with Autism Goes to Town and The Child with Autism at Home.