



Complex Child E-Magazine

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This Stresses Me Out!

by Susan Agrawal

If you ask the average Jane on the street about caring for a child with complex needs, you will probably get an answer something like the following: “I don’t know how you do it. I would be falling apart emotionally. Dealing with those emotions must be so difficult.”

So is the average Jane right? I asked a whole lot of caregivers of kids with varying special needs, medical conditions, and disabilities what stresses them out. While emotions did pop up, they were much less likely to be mentioned than most other things, like problems with the medical system, difficulty with insurance, and handling day-to-day care.

Medical and Other Systems

The medical system, with all its crazy intricacies, was perhaps the most mentioned cause of stress. This is likely because dealing with what is undeniably a broken system on top of all of our other overwhelming duties is simply unbearable. It is near impossible to talk calmly to the lady from the insurance company who has denied your child’s oxygen because only two extremities turn blue and they require four blue extremities. Everything, and I mean everything, is a fight with the medical system.

Insurance and Medicaid received many, many mentions as stressors. Many families particularly mentioned denials for medical formula and necessary equipment. Frequent denials, decisions that render items, “not medically necessary,” or, “items of convenience,” and having to jump through 1000 hoops just to get equipment or therapies were some of the most mentioned issues. A bath chair for a child who cannot sit up is not an item of convenience! Financial issues stemming from uncovered expenses and insurance denials also created a ton of stress for many families.

Doctors tend to be a big source of tension, especially residents. The average parent of a child with special needs has as much specialized knowledge as the average third-year resident. But we lack the ego, big head, and medical license. Obviously, this makes things very challenging, especially when you get one of those “know-it-all.” It is unfortunately rare to find a resident or attending physician who is willing to admit you know more about your child than they do.

Lack of communication between doctors, lack of coordination of care, and lack of communication between parent and doctor were also commonly mentioned stressors. These issues lead to too many appointments, no one seeing the overall picture, and mass confusion for parents, caregivers and home nurses.

Other complaints about the medical system included poor bedside manner, long waits for appointments, incompetent nurses and therapists, medical and pharmacy errors, and having to travel long distances to receive competent care. Home health agencies received lots of complaints, especially regarding a lack of customer service, an inability to provide appropriate supplies or services, and funding or financial issues.

Other systems beyond the medical system also were stressors. Schools, and in particular unfunded and poorly run special education programs, were characterized as nightmarish by many caregivers. Other people indicated that a lack of handicap access, both in the home and outside, including simple access to stores, public buildings, and transit, created a great deal of stress.

Perhaps the most common complaint about systems was just the general thought that everything is a battle. It is a huge battle to get anything done, whether it has to do with insurance, doctors, schools, home health agencies, or any other “systems.” The constant fighting weighs heavily on the soul.

Health of the Child

We all worry about our children. But surprisingly enough, this did not stress us out half as much as medical systems and our overwhelming lives. Nonetheless, many of us are very stressed out by children who cry in pain with no treatment or known source, children unable to communicate their wants and needs, and children who have a poor quality of life. Watching our children suffer through painful procedures is impossibly difficult.

Many of us are in the unfortunate position of having to worry about our children dying. A lack of a diagnosis or prognosis was particularly stressful. Watching a child decline or knowing a child has a depressing or potentially fatal prognosis was devastating for many caregivers. Seeing this information in writing or hearing it from doctors—even if we already know it ourselves—is very challenging for most of us.

Emotions

When emotions were mentioned, they tended not to be the ones the rest of the world expects. The average Jane thinks of grief, coping, and acceptance—emotions that many of us experience strongly early on but that usually pass eventually. The emotions mentioned by our caregivers were much more related to fear and worry. What will happen in the future? Will my child die? What will happen if I die? Am I doing all I can? What if I miss a symptom in my child? Did I make the right decision?

Many parents and caregivers simply seem overwhelmed, physically and emotionally. It was common for caregivers to complain about how difficult it is to be “on” or hypervigilant all the time. It is like a doctor being on-call, except for us it is every day, day after day, for 24 hours a day. Our heads are literally spinning with all of the things we have to manage, as we serve in our roles as caregiver, coordinator, therapist, nurse, cook, and equipment repairer all at once. Add to that the typical duties of the average home, including cleaning, cooking, and taking care of siblings, and you have one crazy busy life! We become slaves to the clock, carefully planning each hour to make sure every med is administered and every medical treatment or therapy is done, between working outside the home, Susie’s soccer, Timmy’s music lessons, and the occasional kiss for your partner.

The sad thing is that what we really need is some day-to-day help. Many of us get next to nothing, even from our partners or spouses, who may not feel comfortable handling a given child’s care. It’s nice that he or she can make that choice. We can’t, and the heavy responsibility of knowing we are the only ones able and willing to care for our children causes even more stress. Instead of helping us out, friends often fall away, unable to understand our new role in life. In some cases, family does not understand the situation and may even be hurtful.

While most people can rely on their family and friends for a night out, it is much more complicated for all of us. It takes three weeks just to arrange it—good luck finding a babysitter!--and after that you are too tired to even enjoy yourself.

Which reminds me that I forgot to mention sleep deprivation. The parents with newborns who complain about a few months of sleep deprivation are living in luxury. Many of us are getting up all night long for years. It makes our eyes burn and our heads swim. But since no one else is there to replace us, we have to keep on going...and going...and going...

Everybody always mentions how important it is to take care of you, your relationship, and your other children. Am I the only one who really has trouble with this? Yes, I squeeze a hot bath in every night and make sure I get one-on-one time with my typical kids each day. But honest-to-goodness “me” time? Nope. There aren’t enough nursing hours, babysitting friends, or caring family members to take up the slack. If I’m lucky, I get four hours once a month. For errands.

Despite all of the emotional stresses we experience on a daily basis, most of us realize that the positives outweigh the negatives. We are better people. We have learned so much. We have changed so much. We truly understand what matters in life. And we just adore our unique kids. That gets us through all the tough moments.

What Can Make Things Better?

Now that I've voiced all our complaints for quite awhile, it is time to focus on solutions. Does it have to be this way? Are there things that could be changed to make our lives less stressful?

The most mentioned change that caregivers want to see is the availability of quality, family-centered respite and nursing care. Many families do not even qualify for these types of services, often because their income is too high or their child's needs don't fit a specific definition required for state programs. Families who do qualify may have problems accessing the service. When pay is typically \$9 an hour for a respite care provider, it is very difficult to find qualified candidates who can be trusted. Other families cannot use respite at all because their children's medical needs are too high for a lay person, but not high enough to qualify for nursing.

Expanding Medicaid waiver and respite programs and making them mandatory covered services would go a long way. It would give families a bit of a break, give caregivers some "me" time, and allow parents to spend more time as couples or with healthy siblings. This type of care must be a quality service from a well-paid and trained caregiver. It must be family-centered and widely available to all children with special needs.

Many families also mentioned that they could benefit from housekeeping and childcare services, such as having an aide come to the home to do laundry, clean, and assist with other children in the household. Thus far, most states have been very inflexible in their programs of this nature. Services are typically only provided to the child who requires them, instead of the entire family. States would save money and families would receive much needed services if the support provided was more flexible and family-centered.

In addition, most families do not receive comprehensive coordinated medical care in a medical home. (For more information on medical homes, see this: <http://www.medicalhomeinfo.org>.) A medical home is not a physical place, but a concept that advocates for family-centered coordinated care, particularly for children with complex medical issues. Having coordinated care from quality healthcare providers would be extraordinarily helpful, and would likely improve our children's health as well.

Insurance and other health care benefits are in a transitional period in the United States right now. I am hopeful—but not particularly optimistic—that changes will be made to make things a little easier for us. I have to admit, however, that having for-profit insurance companies involved in health care is a big problem for me. We need much greater reform in this regard, and this is something we all need to advocate for. Eliminating the daily battles with insurance, durable medical equipment vendors, and home health agencies would make our lives much less stressful. In addition, changes in insurance policy would help many of our families financially, especially those in the

middle class who make too much to qualify for most programs and too little to actually survive with all of their medical debt.

The internet has been amazing for providing emotional support to families and allowing advocacy efforts to flourish. But hands-on support from local families, friends, and relatives is still needed and craved by most families. Many of us ache for someone who understands, someone willing to find out about our child's condition, someone to help out without us having to ask, and someone to treat our children just like any other children.

I hope that in 20 years things will be much easier for families who have children with complex conditions or special needs. At some point somebody has got to realize that helping us out a little bit will save the world a ton on our mental health bills down the road.