

# Parenting Special Needs Children

## Top 5 Qualities of Successful Special Parents

by Teri Brown

Parenting is demanding, joyous, exhausting and fulfilling. If you are parenting a special needs child you can double the emotions – and the exhaustion. It is no secret that special needs children need special parents, but what qualities do these parents need to have?

"Special needs families do best when they are resilient, flexible, open-minded, resourceful and positive," says Karen Krivit, a social worker for Philadelphia Elwyn Early Intervention SEEDS Program and founder of the Philadelphia Autism Network.

It's very difficult for families to even begin to think about what qualities will be needed when a child is first diagnosed, but the following traits will help parents positively and constructively deal with the needs of their very special child.

### **Tolerance**

A child's disability can be devastating on many levels to a family. According to Krivit, the emotions that a family goes through at first diagnosis can include tremendous amounts of guilt, anger and blame. These feelings can become crippling for a family if they are not acknowledged.

"It's important to accept that family members express feelings in a variety of ways," Krivit says. "For example, one parent may be deeply sad and talks and cries to many people, while the other parent becomes quiet and isolated. Both of these parents are expressing sadness but in different ways. Often family members feel that if others aren't behaving as they are, then they are not feeling similarly. It's important to be careful not to criticize each other's coping style, but to give each other the space and validation to have feelings."

### **Acceptance**

Parents harbor many images of things they dream of doing with their children – playing a sport, attending their wedding or even teaching them a favorite song. Krivit says that often a child's disability forces parents not only to modify these fantasies but also to adapt them to their child's true capabilities. "This can be difficult, but it is an ongoing part of the grief process," Krivit says. "Here is where a family must learn to tolerate ambiguous feelings. On one hand, there is an acceptance of limitations; on the other hand there is a need for enthusiasm and hope. Families who are accepting of their child's disability are in a much better place to help each other and that child to thrive. These families can look at their child's strengths, and plan effectively with the child's medical and educational team for the child's future."

### **Patience**

Lisa C. Greene is a mother of two children with cystic fibrosis, and co-author of *Parenting Children with Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness, Medical Conditions, and Special Healthcare Needs* (Love & Logic Press, 2007). In her experience, patience is the No. 1 attribute parents must have as the parent of a special needs child. "When we have children with special issues of any kind, the stress levels of daily living are almost always very high," she says. "Modern day family life can be stressful for anyone, but we operate with a higher stress load than the average family. Frustration is a natural and understandable reaction to the struggles we face when things don't go right, which is, unfortunately, often the case."

According to Greene, frustrations come easily when dealing with the child, their siblings, the doctor, the school, the situation, society, etc. That is the time special parents need to take a deep breath before reacting. "We end up acting out: we get upset; we lose control; we lose our patience," she says. "Things generally don't turn out well for us when we lose our patience – we say the wrong things, we act irrationally and we make mistakes."

Greene suggests that special parents take one day at a time, one moment at a time. Try to stay focused on what can be done right now, in this moment, to improve the situation. Don't worry about what hasn't happened yet.

## **Organizational Skills**

Organization is essential when managing the ever-present details of living with special children. Greene says the more severe the issue, the more critical it is to be organized. A parent simply cannot risk running out of insulin or not having the epi-pen readily available. "Management of medications, medical treatments and doctor's visits can become a delicate balancing act," she says. "For example, our two children with cystic fibrosis take 14 different medications each day between them, and three are inhaled along with doing chest physical therapy. Some can't be taken within a certain time frame of others, so we really have to be organized to manage it all. That's not to mention managing the stock of our meds with the pharmacy, the multiple quarterly doctors' visits – or more when they are sick – and scheduling hospital stays when IV antibiotics or sinus surgery is needed and managing the insurance/finances of all of this."

On top of that, normal life such as schoolwork, social activities, groceries and laundry need to be managed as well. So being organized is a key to saving time, making sure things run as smoothly as possible, avoiding nasty surprises and cutting down on frustration. Greene says it also helps parents to feel like things are in control. "When the engine of the car is purring along nicely, we are more able to handle the extra challenges that inevitably come up," she says.

Julie Turkoske is an information and referral specialist for children and youth with the Special Needs Family Center at Children's Hospital of Wisconsin. She believes it helps to have medical information documented in an organized way. Each school year, parents must provide basic vaccination records, as well as allergies, reactions and other information specific to a diagnosis. When visiting new physicians or specialists, when applying for community-based services, when transitioning to adult services and at other times, families will be asked for specific dates of surgeries/procedures, medications, inpatient stays and other interventions.

"Parents will need to refer to medical – and educational and social – records at various times during a child's life," Turkoske says. "As a parent, it's easy to fall into the trap of thinking that you will never forget the date that your child had a certain surgery or an emergency room visit, but over time those memories fade. Much time and aggravation can be spared if that information is organized and easily located."

## **The Ability to Rest**

Depending on the child's needs, many special parents are sleep-deprived and never off-duty. It is very difficult to be tolerant, patient or organized under those conditions. Sometimes parents just need a break. "Taking care of yourself, as a parent, is important to being able to take care of your child," Turkoske says. "It can be difficult to ask for help or even recognize that a break is needed. It wouldn't hurt to check in with someone who knows you well to see if they think you are tired, stressed or just not your normal self. Even short breaks can help replenish the inner soul."

Just ask Cristina Trapani-Scott of Ypsilanti, Mich. Her daughter was born with a rare form of dwarfism called Kniest syndrome. She stresses that parents of special needs children need to take some time for yourself to recharge your batteries. "One of the biggest things that I'd add is that parents need to not be all consumed with their special needs child," she says. "I think this is one of the hardest things to do. It's OK to let them be a little independent. And parents need a break and deserve a break from time-to-time as well."

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