

Life with Sara **By Cathy Haarstad, Mother**

Our youngest daughter Sara is almost 14 years old. She has Down syndrome, mental retardation, hearing loss and neurological difficulties that result in altered auditory perception and absence seizures. Living with Sara impacts our family in many ways.

Sara is a person who does not wear a mask. She does not pretend. Whatever she feels; joy, frustration, love, disgust, irritation, concern for others or curiosity is communicated immediately without reserve through short phrases and body language. As a result, life with Sara is always honest and never dull.

Sara has some unique needs and a range of behaviors not seen in typically developing children. We learned how to meet her needs and respond to her behaviors. We learned to boost her hearing, calm her irritated auditory and tactile perceptions, control her seizures, teach her basic skills, live with her autistic tendencies and obtain her trust and cooperation. Sara taught us to meet her needs, along with many good therapists, teachers, doctors, relatives, neighbors, and community helpers. It took us about fourteen years.

Sara cannot be left alone for very long. She gets lonesome easily and might open the door to anyone. She can tell you what to do in case of fire but would probably hide under the bed in spite of repeated practices. We can duck out to fill the car with gas or take a short walk. That's about it. A few times, now that she is almost 14 we have left for about 40 minutes to get groceries. But usually she goes everywhere we go. We have adjusted to this by enjoying her company and learning how to rehearse appropriate behavior before EVERY event no matter how common. We have also become skilled at finding sitters, relying on relatives and using respite care. It is a blessing to be able to go for a weekend without having to ask family to take her one more time.

Sara is a very literal thinker. This leads to many humorous incidents that cause us to chuckle but also to appreciate the wisdom inherent in a simple view of life. For example there was the time she observed the blaze set by local fire fighters during their night drill and commented "Oooh! They're going to need some big marshmallows!" Or the time she told us she wanted to enter a radio contest and in a desire to protect her feelings we informed her that we had entered many contents and never won. "Yup! You and Dad are losers Mom but I'm a winner and I'm going to win that contest!" How do you respond to that kind of can-do attitude? Wouldn't the world be better off if the rest of us shared her optimism and joy in life?

Sara is also a very strong-willed and determined person (that sounds better than stubborn) and has many irrational fears. These can dominate family life if we are not careful. Right now she frequently talks about snakes, fires and is terrified of her alarm clock. She has a few narrow topics that she prefers to think and talk about (cartoons and food) and we have to insist that she stay with us in the real world. The lines between remember, imagine and know are blurred for Sara and she easily day-dreams.

This means that we have to be very patient and repeat ourselves a lot. We spend a lot of time explaining the same thing over and over and that can be tiresome. Not everyone reacts to that kind of thing by becoming more patient. Patience is partly a skill and partly a choice. Although patience is not a choice that we made at first, over time it has proved to be a better option for us all.

We have had many celebrations with Sara and some tears. We celebrated the first time she was invited to a party and cried when she outgrew her first friend. We wince when we hear the words moron, idiot, and imbecile used by friends and on sitcoms and rejoice when she hugs us many times each day. We smiled when she “pinky swore” with her best friend to protect her family forever and celebrated the day she received her hearing aids and announced “Mom, I heard a bird.” Sara’s smile is an extremely powerful tool and until she came into our lives we had no idea how important it can be to make another person happy.

Many supports or services that would make our lives easier are not available and we choose to continue to live in our community in spite of those circumstances. We are not concerned with having the ultimate. It is harder when we see what could be but what we must go without because a principal or teacher is not aware or trained or a system is not prepared to grow unless we make advocacy a full time job. Unfortunately we have to earn a living and want to have a life. So we do the best we can to get Sara what she needs and avoid conflicts we think we cannot win. Living with Sara is enough risk for us. And she thrives in spite of it all. Someday we hope Sara and children like her will thrive because of it all.

Many parents claim that having a child with special needs makes them a better or stronger person. I think that any kind of pain, whether it is a dying parent or the loss of a friend to cancer can challenge us to re-examine our lives and recognize what is really important. In our society we put great emphasis on intelligence but the truth is that God does not love us for our brains, our perfect bodies or even our great personalities. We are loved as we are and called to be love for one another.

Not everyone meets a serious life-challenge by coping or becoming a “better person.” People fall apart, marriages break up, resentments grow and anger can become a way of life unless we choose otherwise. We are not privileged to see what might have been had Sara not come into our lives. We do not know what other challenges may have come our way or wait in the future or how we might or will respond. We only know that God has set before us life and death. We choose life.

We love our children and our hearts break when we think anything might happen that would put them in harm’s way. Our choice to love and keep Sara has started a chain of events that continues to evolve and lead in new and surprising directions. We can’t wait to see what will happen next and how the story comes out.