

Chapter One

What is Autism?

The sun felt warm upon my back as Daniel and I strolled together across the lawn. Our chores were done and now we had time to relax. He unexpectedly reached out and gently took my hand, guiding me in the direction of the house. Willingly, I went with him wondering at this new and unusual behavior. As we passed through the door and headed into the back of the house, I realized that he was going toward the bathroom. He used the bathroom; and, after he had flushed the toilet, he turned and smiled directly at me. Again, he gently took my hand and we quietly returned to the driveway. I sat down in a chair while he began playing with his trucks, using the low cement wall as a roadway.

To many, these simple actions would appear to be the regular interaction of an adult and child, but for me they were incredible, unbelievable gifts. For Daniel is autistic. At the age of 10, he did not go to the bathroom on his own. He wore diapers. He did not play with trucks like any other child. He did not approach others for help. However, on that particular day he did. I was stunned at the abrupt change that had occurred and wondered what had brought it on. Twelve years later I look back on that day with a special reverence, for I had been allowed to spend a few minutes of time with a stress free autistic child. In those brief moments we have the opportunity to recognize who an autistic person is and what they are capable of.

In 1988, Daniel lived in a group home on a farm with two other adults diagnosed with autism. The group home provided care on a 24-hour basis and had staff members who worked varying shifts. This was a special day because the other two adults and their staff had left early in the morning to take our lambs to the auction mart. Daniel and I were alone on 160 acres of land. We did the morning chores, took a walk, had a quiet lunch and then spent a while weeding the garden together. Now with our tasks complete, we had time to relax. And in those moments Daniel was finally free to be the person he is meant to be. This happened because he had spent the day in a stress free world and was feeling completely safe. In a couple of hours the other men returned and everything went back to normal. I never again had the opportunity to be with that calm, gentle, capable child because in order to be stress free, Daniel had to feel completely safe. That wasn't the world he lived in at that time.

The Diagnostical and Statistical Manual of Mental Disorders¹ states that autism is a severe, lifelong developmental disability which expresses itself through an impairment in the ability to communicate with others, an impairment in the ability to socially interact with others and the use of repetitive and stereotypic behavior which may not appear to make sense to the general public. The condition may occur alone or in association with other disorders. It is essential for anyone who is working or living with someone who has autism to understand that these three conditions are symptoms of autism, and do not, in any way, describe what autism is, in much the same way that a cough is not a cold, or red spots are not measles. They are only symptoms.

¹ American Psychiatric Association (1994), *Diagnostic and statistical manual of mental disorders, fourth edition*. Washington, DC: American Psychiatric Association

Throughout the past twelve years of working in this field, I have come to realize that the symptoms, as described in the DSM, are a direct result of the high level of stress that autistic people live with on a day-to-day, minute-to-minute basis. Autism itself is so much richer and more complex than these three symptoms. Although every autistic person is truly a unique individual in their own right, they do share several characteristics that separate them from the rest of the world². I believe that the recognition and understanding of these characteristics are the keys to unlocking the potential of each autistic individual, both for themselves and for others.

Truly understanding an autistic person means creating a situation in which that person can be stress free, in order for the person to be free to react without using their many coping skills. It is only when the autistic child or adult is relaxed and stress free that the “true-face” of autism can be seen. However, the characteristics of autism are always in place and affect the interactions between themselves and the world. Becoming aware of these characteristics allows us to interact with them without adding to their level of stress as we work and/or live with them.

A stress free autistic child is a happy, well-behaved child. This statement may be somewhat of a surprise to many, and some may automatically disagree because of their own experiences. However, one has to realize that an autistic person is rarely in a situation in which they are completely stress free. Thus, the behaviors that so many see as inappropriate or negative are the direct result of stress, not autism. As Neil Clarke, an autistic man from Australia states “negative symptoms don’t exist in autism in the first place. They are survival strategies for the anxious child.”³

Celebration of Life

When an autistic individual is stress free, he/she is capable of doing anything that other people do. That’s why Daniel was suddenly able to use the bathroom on his own and played with the trucks like any other child. He was dealing with too much stress to be able to carry out these simple functions the rest of the time. The more stress in a situation, the more apparently inappropriate the behavior and the apparent inability to do things; the less stress, the more we see of the real person. Once we realize this fact and make the effort to remove the stress from their lives, we have the opportunity to get to know these people as they truly are.

Autistic people are filled with a joy of creation and relish the incredible beauty of the world that we live in. They take the time to enjoy the very simple miracles that our lives and our earth have to offer.

² Portions of this chapter have been adapted from a speech prepared and presented by Carolyn Baird, BA to the Newcastle-Hunter ADHD Support group meeting, February 16, 2000 in Newcastle, New Zealand. Used with permission.

³ Neil Clarke, personal communication, Australia. Used with permission.

I remember one time when I was little, just this sandy haired little boy in farmer jeans and a red shirt about three, maybe four, years old, wandering about the neighbors open backyard all curious about the going-ons around me. The whole world seemed to flux and glow in brilliant bright color: like some wide open swirl of bright greens and blues with speckled dots of brilliant yellow at my feet. The sun was warm on my face and the morning air was filled with pleasant scents. I remember feeling so calm and peaceful.

The green was grass and the blue was the sky. The yellow dots were buttercups that I plucked and touched. The sweet smells were from fragrant rows of lilac flowers that divided the property: purple ones and white ones that rained down in showers when you shook their branches back and forth. And I looked at the sun with my eyes closed and saw that translucent orange color, and I felt that this must be the color that happiness and pleasantness was: lost in the fuzz.⁴

The celebration of creation is a special gift that is rarely mentioned in connection to autism or respected by many people in the so-called normal population. However, those who live with this condition know that it is there. In a letter to an anxious mother, Scott McGifford states:

I just want to reassure you that autism isn't all bad and nightmarish. When I was nine years old, I sat in wonder, looking at the butterflies, splendid colors, marveling at hummingbirds or at the colors of flowers, bumble bee hums and summer smells. I liked the attention from my mum when I got stitches or had a broken wrist. I liked sleeping next to my dad on the hammock in the summer or listening to people talk about me when they thought I was sleeping. I liked being carried up to bed when I pretended to fall asleep in the car.⁵

A young mother recently discovered this characteristic while on a walk with her son.

I took my son for a walk the other day, and I was dying to know what was going on in his little mind. He stopped along the street, at a storm drain, laid down on the street in a huge puddle before I could stop him, and started giggling at the water running into the drain, both from the puddle as well as in-feeding pipes. How do I know this? Well, as we live on a very quiet street, and it seemed he was getting such a positive reaction to whatever he was watching, such joy, that I laid down in the puddle with him to see what was going on. Without any words spoken between us, we communicated so strongly, in a way that no words could capture. His music I could ever imagine. The sound of the water running in the

⁴ Scott McGifford, unpublished manuscript, used with permission.

⁵ Ibid.

pipes otherwise would have just meant exactly that...water running in pipes. Now to me it means a whole new world exists with those pipes, and a whole new world is opening up every day with my son. I actually made contact with my son in a way that very precious few other people care to take the time to do.

To some people it may have been a seemingly insane mother laying in a puddle with her son, and not having the common sense to chase him out of the puddle. A cameraman could never capture the world that we shared looking into that drain. An editorial/magazine article couldn't ever express the bond shared between my son and me on that precious and rare moment. No, no one could ever pick up on the miracle that happened at that puddle. I just know that was a moment straight from heaven, one that people who want to shed a light into the world of mentally challenged people never want to work hard enough to get. Makes me glad (maybe a bit selfish) that we can spend such moments with our children without being intruded on. It also makes me sad that it seems that these experiences don't seem significant enough to go the extra mile to get.

That puddle didn't cost me a thing, except a load of laundry and a shared cup of hot chocolate when we got in. I sure wasn't worried about dignity, as none was lost. It was great therapy for both of us and brought my son out of his own little world just a little bit more.

My son took an ordinary puddle and a storm drain and made it into a magical world for me. It gave me an escape from life for a brief (albeit wet) minute, and led me straight into his life, one that is sometimes too overwhelming to deal with. Guess over all, I am sad that this side of people, not only their gifts for the odd mixture of abilities and inability's (as Mr. Sacks puts it), but what these people do for the lives around them from an extremely young age, is just not important enough to show. This child has given me more self esteem in myself, given me a reason to live, and gave me a much needed challenge in my life that no one else can quite live up to. I used to ask God "Why me?" now it's "Why not everybody?" I was truly blessed when God selected me to be Kyle's mother.⁶

In her book *Life Behind Glass*, Wendy Lawson describes an encounter with a cicada emerging from its hole at 6:30 A.M. on a hot summer day.

I watched this creature transform before my eyes from a dull brownish-green bug into a beautiful bright and gold singing creation. The process took only one and a half hours. Apparently this large larva spends seven years underground. I understand now why it needs to sing so loudly when it grows its wings. I was so excited to catch this experience and be in on this creature's birth. Many people passed by and I told them the cicada story. I have heard

⁶ Caroline Parker, mother of Kyle, personal communication, used with permission.

since that people thought my standing in the heat for one and a half hour to watch an insect was a crazy thing to do. I think it is they who are crazy. By choosing not to stand and watch, they missed out on sharing an experience that was so beautiful and exhilarating. A miracle happening all around us and not one is aware of.⁷

As a family and marital therapist, I find that many of the so-called ‘normal’ people I work with are so filled with negative emotions such as jealousy, guilt, shame, distrust and so on that they have no way of knowing how to feel simple joy. It takes hours of therapy for them to go out and find simple pleasures in life. Autistic people do not have this problem. Even in the midst of the chaos that we force on them, they are able to rejoice in simple things: the shape of a building, the feeling they get from touching a certain object, the sound of a single word. Our world is filled with treasures to celebrate and autistic people take the time to appreciate them.

Dan Reed, author of *Paid for the Privilege* discovered how they interact at a higher level when he took several clients with autism to visit the artist Padre Johnson.

Aaron was the next to ask, “What do you see when you see the sky and water?” I was assisting Aaron and honestly did not know what Aaron was talking about, but Padre knew.

“My friends, the blue of the sky and the water is seen in every face I draw. We are all born to this planet. We are all part of this earth,” said Padre. Aaron nodded that he understood. I responded, “Oh.”

The questions continued. And they continued to impress Padre. He and our clients seem to be on a plane different from the rest of us. Knowing little about art, I was trying to pick up as much as I could from the discussion going on around me.

Padre started talking about the Bushmen of southern Africa, the people on whom the movie *The Gods Must Be Crazy* is based. He said “The people are the most wonderful I ever met. They love, nurture and respect each other like no other society on earth. They don’t even have words in their language for hate or murder.” He continued, “You people have that same peacefulness and sense of goodness that is far too rare in our world today.” As he choked back tears, he continued, “Please forgive me for being so emotional but I feel a love and appreciation for life in this room that I seldom feel. This visit has meant a great deal to me. Thank you for coming;”⁸

⁷ Wendy Lawson, *Life Behind Glass*, Lismore, Australia: Southern Cross University Press, p. 115. Used with permission.

⁸ Dan Reed (1966) *Paid for the Privilege: Hearing the Voices of Autism*. Published by DRI Press of Madison, WI, p. 88-89. Used with permission.