



## **Beneath the Surface Understanding Autism**

**by Kelly Burgess**

Raising a child with autism is a different, often bumpy road to travel. It can also seem like a long, one-way street. Needy and self-absorbed, the autistic child doesn't "fit" into what most people consider the social norms. And many people aren't shy about pointing this out.

In her book, **Souls: Beneath and Beyond Autism**, author Sharon Rosenbloom writes, "Unlike those whose limitations are obvious, people with autism wear the mask of normalcy. Their faces do not betray the burden they carry, yet their actions invite rash judgment on themselves and those who tend to them."

Rosenbloom speaks from experience. In her book, she recalls a luncheon she had with her son, Joey, who is autistic. As they were leaving the restaurant, her son reached for a lady's wallet lying on the corner of a table. The lady self-righteously accused Rosenbloom of bringing an untrained brat out into the world. Angry and ashamed, Rosenbloom could not find the words to defend herself or her son.

### **Finding the Words**

That incident happened many years ago. Since then, Rosenbloom has come to terms with society's misinformed view of people with autism. From her experiences and the experiences of other parents with autistic children came the book, *Souls: Beneath and Beyond Autism*. It's not an informational tract about autism or a guide to caring for an autistic child. Rather, it's a work that carries a larger message – don't be so quick to judge a book by its cover.

Appropriately, the original idea for the book came from a person who is accustomed to looking beyond the surface, photographer Thomas Balsamo. A photographer for 25 years, Balsamo believes that the eyes are truly the windows to the soul. For years, he's had the idea of a book that would explore that theme, but with a deeper meaning behind the pictures. He had known Rosenbloom for many years and had photographed Joey many times. At one of their visits, when Rosenbloom was talking about Joey's autism, it all just clicked.

Balsamo was inspired by two experiences working with autistic children and their families. One, which came rather early in his career, was when a mother called him and asked if he thought he could capture the true relationship between her three daughters. The girls were all very young, and one was autistic. The mother knew of the unique and beautiful relationship between the three girls, but because autistic children do not "bond" on command, no photographer had been able to capture that bond. Balsamo said he'd do whatever it took to succeed. The little girl was very distractible, and it was a time-consuming photo shoot, but the results were amazing.

Ten years later he had an opposite experience. A family he had worked with many times showed up for a sitting with an older boy they introduced as their son. He was present during the family portrait discussions, but when the time came for the portrait, they left the boy to sit in the waiting room. As Balsamo later discovered, he was in an institution and was just home for the weekend. The family didn't even want to acknowledge their tie to him.

"The first experience helped me to learn a lot about both life and portraiture, and the second devastated me," says Balsamo. "He's really the reason I did the book, because I know there's something beautiful behind these seemingly emotionless children."

### **Beneath the Mask**

The fact that Balsamo did not know that boy was autistic, nor did he know that Joey Rosenbloom was autistic until Sharon told him, is telling. This, as Rosenbloom explains it, is what can make life doubly difficult for the parent of an autistic child.

"The world can judge autistic children very harshly," says Rosenbloom. "Part of the problem is that these children wear a mask of normalcy. You can't see anything wrong with them – they aren't in a wheelchair or afflicted with an obvious genetic condition that you can adjust to. After reading this book, there is no way that you can say an autistic child doesn't have feelings or emotions."

The danger in those assumptions is that it can serve to further isolate autistic children and their parents in a society where parenting is already individualistic to the point of often being isolating. We do not have villages or communities to raise our children; we raise our children. As a result, parents who take an autistic child out in public, instead of meeting compassion and understanding for the challenges, often are scorned for not being strict enough.

Even more distressing is that parents are often given extremely negative information when their child is first diagnosed. Sometimes they're told that the child will never relate to them, will never be able to function or communicate and will never overcome their disorder. It's not unusual for institutionalization to be recommended. This attitude is potentially robbing those families of an incredibly valuable bond with their special child. Rosenbloom writes, "Being loved by someone with autism is a cherished and coveted experience perhaps because when loved, we are linked to him or her in a manner that transcends surface layers."

### **The Rewards**

That connection, that unconditional and nonjudgmental love, is the great reward of caring for an autistic child. A surprise embrace, a smile at bedtime, suddenly hearing your child call you "mommy" for the first time in, perhaps, weeks or months are moments that carry the parent across the difficult times.

In summary, it's not about autism, and it's not about "them." It's about us. What readers can take from this book is both on the surface – that children with autism have been misunderstood, that parents have been misjudged – and hidden – that everyone has a soul.

Note: **Souls Beneath and Beyond Autism** is available at Rapid City Public Library. I recommend it. It touched my soul.