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## NORTH OF THE BORDER

[ BY GAY AND DENNIS DEBBAUDT ]

*(Gay and Dennis Debbaudt are the very proud parents of Brad, in his midtwenties, diagnosed with ASD well before autism became a mainstream topic of discussion. They have handled his diagnosis with diligence, compassion, and humor. —RP)*

Pillows, towels, and blankets? Check!

Favorite foods and beverages? Check!

Flashlights, camera, radio, and batteries? Check!

Our predawn packing completed, we were ready to spend a long weekend at our friend's across-the-border cottage on a Georgian Bay Island.

The trip in our very cool van would take about five hours. We were taking the back road route along the eastern shore of Lake Huron to avoid the heavy traffic on Ontario's Highway 401. So we drove north from Detroit to Port Huron, where we would cross into Canada at Sarnia via the Blue Water Bridge.

Welcome to Canada

About fifty minutes into our journey, the brilliant morning sunshine illuminated the beautiful view from the bridge. On our left, Lake Huron's green waters mingled with the clear blue of the Saint Clair River as it flowed under us from the right. Traffic was light on this crisp, clear early summer morning. The Canada Customs and Immigration post came into view as we passed into Canada at the bridge's midspan.

Growing up in border city Detroit, one becomes adept at entering Canada and passing customs. At Detroit-Windsor customs, for example, you wait your turn, pull up to the inspection booth when directed, and answer the standard questions, which are typically directed to the driver's side of your vehicle.

"Citizen of what country?" "Where are you going today?" "Business or pleasure?" "How long will you be in Canada?" "Are you bringing in any weapons?"

We've heard the spiel hundreds of times.

Canadian customs at the Port Huron-Sarnia border was different. You had your choice of pulling up near the booth from either the right or left. There, Canadian customs agents step out of the booth and approach your vehicle, presumably to get a better look.

We pulled the van up to the left and stopped. We were all wide awake and ready for Canadian customs Q and A.

Our van at the time featured two captain's chairs in front and full carpet in the back. The front passenger side was the only appropriate place to plant six-year-old Brad's comfortable child seat. He loved the lofty view.

A pretty, young Canada customs agent popped out, resplendent in her crisp, blue uniform and neat dark blue bowler that featured a gold maple leaf hat badge insignia.

Brad's window was already down for the fresh air when she approached our van at the passenger side window. As she leaned in with a look of

confidence about what we expected would be the standard questions, Brad reached out with his right hand and gave her left breast a full and firm grab. Her face showed surprise and embarrassment and was as red as the maple leaf pin on her uniform top.

She lurched back, and quickly waved us through without a question being asked.

Welcome to Canada!

We laughed all the way to our destination.

We'll never know why Brad innocently groped the customs agent. He'd never done anything like that before, and hasn't since. Was it the sudden invasion of his personal space? Was he reaching out to touch her shiny pin lapel?

Of course, the agent couldn't have known Brad was riding shotgun with a diagnosis of autism. It was something we had discovered only three years before.

## First Steps

That was spring 1987. After months of testing that included videotaped play, games, examinations, and interactions with the staff, we were given an appointment to come to the office without Brad.

The very nice psychiatrist at Children's Hospital of Michigan in Detroit announced Brad's autism in a friendly, matter-of-fact manner: "Your son has autism. There's no cure. He'll always seem odd or different to others, but with special help he can learn some independence skills and, hopefully, learn to read and write. He'll have difficulty accepting changes in his routine. He has a fascination with letters and numbers and will take great comfort in these things since they will never change. There's no way to determine what life will be like for him as an adult, but you, as parents, can make a big difference in how he learns and accepts his autism."

The doctor suggested we find out all we could about autism and get involved with a support group. He recommended that we take advantage of any special programs the school system offered.

We both grieved and cried during that drive home. It wasn't the first time we had heard the word *autism* associated with Brad. Family and friends

familiar with the symptoms of the diagnosis had hinted at it. But you can't really prepare yourself for the day you hear the words spoken with certainty.

Nonetheless, we quickly reached the conclusion that our attitude toward our young son and his condition in life could make a big difference. It was, after all, his life we were talking about, not ours. We vowed in the car that day to do all we could to educate ourselves and our son about autism. We would find a way to give him every opportunity to live a full, independent life. Autism or not, we would show the world to Brad and show Brad to the world.

We told him he had autism as soon as we got home that day. We explained we would help him learn to communicate and help other people understand his autism. As a three-year-old, we couldn't know what he took in from the conversation, but we've spoken openly about autism in front of Brad ever since. We told Brad that it's OK to have autism and OK to tell other children and adults that he has autism. We also let him know that it would always be his choice to tell others.

## Reaching Out

We contacted our local chapter of the Autism Society of America and started attending local meetings, especially keen to connect with the parents and families of teens and young adults. We wanted and needed a glimpse into Brad's future. It felt good to be with other families who had been there and hear from the teachers and therapists who worked with them. They kindly shared their experiences and advice. We learned that no two persons who have autism are alike, yet they have many experiences in common, including educational and therapeutic choices.

The Internet wasn't available to us at the time. Autism bookstores back then could feature only enough materials to fill a card table. So, it was learn what you can when and where you can.

We connected through the support group with a savvy Detroit public schools autism consultant. While discussing Brad's future, she offered us some sage advice: "Don't worry about anything he's doing now that won't matter when he's an adult. Worry now about what he's doing that will get him in trouble when he's an adult."

Great advice, we thought. Don't sweat the small stuff.

Of course, we took advantage of all the speech and language, physical, sensory, and occupational therapies offered by school district professionals. We supplemented that with private therapy. We desperately wanted Brad to be able to understand the words and ideas that came from the pages of books and the mouths, facial expressions, and body language of others.

We also invested a lot of patience and time with pediatricians who treated his symptoms of a bad rash, diarrhea, and weight loss without looking for the cause. On a recommendation from a friend, we went to see her holistic doctor, who recognized it as a tough intestinal yeast infection. He told us that *Candida albicans* infections were not uncommon for children with autism. Brad was put on a sugar-free, yeast-free diet; we joined him to make it easier for him. Brad was also put on active cultures, acidophilus, and bifidus. His symptoms improved within days, and to our surprise so did his behavior and learning progress. We all developed an affinity for cashew butter on rice cakes.

We spent money we hadn't earned yet to give him auditory integration therapy.

We subscribed to the belief that if a treatment, therapy, or educational program didn't hurt him—and if we believed it might help—then it was OK to give it a try. It's OK to make a mistake. We also came to understand that it was all right to stop something that wasn't working.

Patience is a concept we've always believed in. We were patient with the therapies and specialized teaching methods, and Brad was patient with his parents' and teachers' skills in making them work for him. Developing patience with and for each other is not only a concept but truly a virtue.

Brad needed an aide during those early years in school, but this was something we could not afford. So Gay set aside her career as a professional seamstress to take a job as a teacher's aide for another classroom to free up an aide for Brad at the Montessori school he attended from kindergarten through sixth grade. This allowed Brad to have an early one-on-one teacher's aide and gave Gay and the teaching staff the opportunity to quickly identify and address learning and social issues before they became too onerous to resolve.



## The Learning Curve

Our children may be more resilient than we think. It's not easy to gauge progress when you're involved in a day-to-day learning process, and it doesn't come fast; but it does come. Progress didn't happen overnight. With parents, teaching staff, and especially Brad all working together, we made it work.

He learned to read the books he loved to have read to him as a youngster. With help from school and private specialists, his shaky, left-handed handwriting improved. He slowly learned to take turns on the playground. He excelled in art and music. He was learning how to learn. Of course, we were all thrilled.

Then we remembered what the autism consultant told us just after receiving the diagnosis. Was the academic learning the big stuff, or the small stuff? Were we focusing on the academics too much? Would it matter during his adult life if he added two plus two and came up with five? After all, we hire accountants to prepare our taxes and rely on the talents of many others for the services of a lifetime.

Were we worrying enough about the things he was doing now that would get him into trouble as an adult? Would it be acceptable, for example, for him to grope a customs officer? hug a stranger? cut in front of a husband to talk to the man's wife? How would he react when a police officer suddenly appeared on the scene? Would he understand a sexual come-on? Would he be able to tell the difference between friend or foe?

Perhaps this was the big stuff after all!

To improve his community life skills education, Brad learned how to ride a bike and stay on the sidewalk. We practiced crossing the street, teaching the significance of street signs and traffic lights. We took frequent trips on public transportation: buses, trains, even on a plane. We took trips to see family and friends, to restaurants, to ball games at Tiger Stadium, and to shopping malls.

Two incidents, however, made us reflect again on the big stuff.

One was when my son disappeared while we were visiting my brother's house. He was found after a frantic fifteen-minute search, only after my brother's neighbor stepped out of her house and with a grin on her face



called out to us, “Is this yours?” as she displayed my young son proudly in her arms.

It turned out that as we were greeting my brother’s family on their front porch, our little guy walked through their house and went out the back door and down three yards into the back door of the neighbor’s house. The neighbor found a complete young stranger in her family room playing contentedly with her own kids’ toys.

## Walking the Line

Another important incident happened during one of those shopping trips as we were stopped and quizzed by mall police on suspicion of child abduction. This was what other shoppers had observed and reported to police when they saw Dennis struggling with Brad during a behavioral meltdown inside a toy store.

These incidents rang a bell for us. What would the police have done if they arrived to find Brad as an adult alone, throwing a tantrum in a store? What would happen if, as an adult, he wandered into an unsuspecting neighbor’s home? Would the neighbors grin and bear the intrusion from a strange man? Probably not. It would be more likely for police to respond.

What this meant for Dennis was an unexpected career choice: educating law enforcement about autism. Researching, reporting, and producing training videos and tools about the interactions between children and adults who have autism and law enforcement professionals is now a reality for Dennis.

For Brad, these life skills lessons started early. We created simple, printed rules that we signed and posted on the refrigerator:

- You can’t push or hit other people.
- You can’t destroy your property or the property of others.
- You can’t say you are going to hit or destroy property.

Brad asked what would happen if he did. We could have said, “Oh, you won’t be able to play with your favorite toys or watch your favorite video.” Instead we remembered the big-stuff advice (what if he did this as an adult?).

Our answer reflected the adult reality of such behavior: “You’ll go to jail,” we replied.

An eight-year-old, Brad asked questions about jail. We told him in plain terms that jail is a place where you have no choices about what you do, what you eat, where you can go. We offered to take him on a tour of a jail. We even drove by a correctional facility. He saw the concertina-wire-topped fences and decided that he didn’t need a tour.

Of course, we didn’t hound him or pound this into him. We didn’t remind about the rules when he got into a little trouble. We talked about the rules occasionally, never in the heat of the moment, and included ourselves as people who needed to follow them. He got it, and he follows them religiously to this day.

## Developing Empathy

We were married at downtown Detroit’s historic Saint Bonaventure Chapel, a nineteenth-century building located little more than a stone’s throw from the Detroit River. This was also where Brad was baptized. The remains of Father Solanus Casey, Detroit’s healing priest from the 1930s through the 1950s, are interred in the chapel. The Roman Catholic Church is considering Father Solanus for sainthood.

When we told Brad about the chapel’s midweek, early-afternoon healing service, he wanted to go. We attended the healing services for about a year. After a short prayer, the informal service offered the opportunity for those in attendance to raise their hands and talk about spouses, sons, daughters, relatives, and friends in need and ask for the group to pray for them. Brad preferred to sit away from us during these services. He wanted to meet new people; he did, and he was very popular.

Sometimes Brad would bravely raise his hand to ask for a prayer for a new friend he was sitting next to. As the priest came around to pray for each parishioner, Brad would touch the priest and the person’s shoulder next to him. This would create a special, physical web of people praying for one another. We could actually see the web from where we were sitting, oftentimes teary-eyed. Brad is very spiritual. Just short of a miracle, the whole experience helped improve his communication and social skills. There is nothing like the power of prayer.

## Academic Life

We learned the value of developing good relationships with educators early on. Brad wanted to do well in school, but challenges—ranging from being left-handed to discovering the hidden meaning of stories in his “Great Books” class—were very difficult for him. Classes that required memory skills such as Spanish, Chinese, and music came easier.

It was also very helpful for us to learn the rules of the Individuals with Disabilities Education Act (IDEA) and the in and outs of working with educators to develop Brad’s annual individual education plan (IEP).

While Gay was occupied with Brad’s everyday care and the nightly rituals of homework, Dennis went to IDEA and IEP parent education classes. As a result, we gained a better understanding of the rules and realized that parents and educators truly have the same goals in mind: the best interests of students with disabilities.

Sure, there were contentious meetings over the years. But the training and positive partnerships that developed gave both sides to the ability to dismantle or work around any roadblocks. We learned that what’s reasonable and fair for everybody in a meeting room is often what’s workable and doable in the classroom.

When it was time to move on from Montessori, we wanted and needed Brad’s input about where to attend high school. Brad chose a public school for students with autism. He was intrigued with the idea of attending a school where no one would tease him for being different, a school where, as he put it, “They know about autism.” Brad had never attended a center-based school, but the reasons for his choice were sound. He would go to a school where they got autism.

During a visit to the school while class was in session, Brad asked Gay to come meet a new friend. Brad’s friend was sitting on a bench in the hallway as school was letting out. As Brad and Gay approached him, he looked away from us and rocked back and forth. Brad said, “I would like you to meet my Gay.”

While still looking away and rocking, to Gay’s surprise this young man extended his hand to shake hers. Brad later told us his friend didn’t speak at all, but he understood everything. The teachers knew this all too well. They

taught all subjects and social skills in the belief that their students would eventually get it—and they did.

Brad learned the value of patience, empathy, and sympathy. He was neither the first, nor more important the last, person to get it socially or emotionally. By making friends with other students with autism, his personal understanding of the condition quickly expanded. He learned the lessons of patience, empathy, sympathy; he learned to advocate for himself.

In addition to academics, the school also offered life skills and vocational opportunities. Brad worked at a nursery and a hospital. He tried things he had resisted in the past, such as field trips to Toronto, museums, and the state Capitol. He found out he could have fun with people who knew about and accepted his autism. Brad's three-year experience at this school broadened his vocational, social, and academic horizons beyond anything we could have imagined.

## Sharing the Wealth

Brad's last two years of high school were in an inclusive environment in Florida. Although the new kid, he was one of only a few students with autism who had ever attended that school.

We had moved to a fast-growing region of the state and into a school district where autism was still something they were learning about. Since Brad was in an inclusive setting, we and district administrators—of course, with Brad's approval—agreed that students and staff would benefit from an autism awareness inservice session. We feel strongly that informed students are more likely to accept a peer who has autism.

We offered to talk with Brad's classmates about autism and the fact that Brad had it. Our offer was accepted.

We were given about fifteen minutes to explain autism and tell a little something about Brad to the other students. We knew from experience that to get accommodation for something people have to know that they need to accommodate. We knew that Brad required some extra eyes and ears to keep him safe on the campus. We also knew that isolation due to disability is a reality families live with every day.

So, to create some accommodations and hopefully a friend or two for Brad, we made isolation owing to autism a part of our talk.

To explain isolation, the class was asked how times over the last month a friend had dropped in on them or given them a call at home, or how many times they saw a friend in the community and hung out for a while.

One of the girls who raised their hand responded by saying, “Oh, maybe, like . . . a hundred.” Many others nodded in agreement. The male response was summed up by one fellow who said, “I dunno, maybe ten or fifteen.”

The class was told that Brad had had about ten or fifteen contacts like that *in his lifetime*. Social isolation is a reality for many young people with autism. Social contacts that aren’t a result of an IEP meeting or plan developed to get peers to interact with them, that is, naturally occurring social contacts, are hard to come by.

The talk did the trick. His classmates learned something about autism about someone in their midst who had it. With disclosure, Brad’s social contacts increased.

A gang-color-wearing classmate took an interest in Brad. When Dennis learned of this, he approached the young man at a school basketball game. The fellow told Dennis that Brad was an interesting guy. Dennis asked the young fellow to keep an eye on Brad at school, so that other students who didn’t know him might not take his autistic mannerisms (standing too close, talking too loud, or not getting what was said to him) as an act of defiance or sign of vulnerability.

He replied, “Don’t worry, Mr. D. Nobody’s gonna bother Brad.” Amazingly, no one did.

Brad took drama class and produced an acclaimed music video seen by many at the school. This got him instant recognition as a cool peer. He became a semicelebrity for that short video. He heard his self-proclaimed nickname, “Fumbles,” in the hallway from people he did not know. Student athletes, girls, and others became school friends.

## Into the Future

Brad’s credits from up north were approved at his new school, and he took night classes and worked with tutors to be able to pass the requirements necessary to earn his high school diploma. Though never easy, and always exhausting for him, all those years of hard work paid finally paid off.



In front of thousands at the graduation ceremony, Brad took the walk in his cap and gown for his handshake and diploma, accompanied by applause and cheering from the crowd and the low rumble of “Fumbles!” emanating from his classmates. A proud moment, indeed.

Brad is twenty-three now. He graduated from high school with a 3.2 grade average and recently received his Class B commercial drivers license. He loves listening to and playing on his guitar his beloved jazz and rhythm and blues. One of his goals is to hold the world’s record for giving blood. He’s been donating every fifty-six days since he turned eighteen.

We are proud of him and all the other resilient autism spectrum children and adults who are giving their best shot at making the most out of everyday life.

We know he couldn’t have achieved these goals without the help our family has received from good and caring professional educators that we’ve had the privilege to form partnerships with over the years.

For all of you, we are extremely grateful.

