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Robert Naseef PhD

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SPIRITUAL ENCOUNTERS

When the Bough Breaks:

A Father's Story

Robert Naseef, PhD

ABSTRACT. The diagnosis of a child with a disability is often the harbinger of psychological and spiritual crisis for parents as well as an opportunity for growth. This essay looks at the grief and the transformation from the viewpoint of a father of a child with autism and mental retardation. The writer, who is also a psychologist, explores the agonizing decision to seek a residential placement which is currently unpopular but sometimes necessary.

KEYWORDS. Autism, fatherhood, grief, residential placement, unconditional love, spiritual growth

Dr. Robert Naseef is a psychologist, author and speaker.

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Over twenty years ago, I held my newborn son's soft delicate body next to my heart. I was swept away by the electricity of the moment. My heart pounded with excitement. He was all I had dreamed as our eyes met and locked onto each other for the first time. In a quiet moment, I can still smell him and feel his tender skin next to mine. Like magic, he made me a father with visions of playing baseball and building model airplanes together.

That I would someday lose this perfect baby was beyond anything I could fathom. How could it be that he would grow to adulthood and not read or write or speak? What would make it necessary for him to grow up in an institution? What could possibly drive me to such a decision? How I could mourn the loss and resolve the guilt over the past twenty years is told here.

Tariq's life flowed through the first eighteen months. Everyday seemed to bring something new. At four months old, for example, he began to lift up his head and look around. I took a picture of him that I still prize. There was an amazing resemblance to an old picture of me that my mother had taken at the same age.

A month later he began to creep and then crawl. It was so much fun to see and feel his excitement. There was a gleam in his eye as he motored himself at will around the house, pulling himself along with the help of the furniture to get where he wanted. His explorations prompted more care to keep him safe. He had to be steered away from the steps or the fireplace.

By his eighth month, he could pull himself up to a standing position. He beamed with such sweet pride. He would glance around and plan his route to whatever looked like fun. A few weeks later he began to "cruise," holding onto furniture and getting around upright whenever he could. Frequently I would hold his hands above his head and walk behind him, full of anticipation. His first steps would come any day.

Before long it was his first birthday, and his initial baby steps came. I can still recall the look of apprehension and then the thrill expressed with a smile as he took those first awkward, wobbly steps. I was so proud of him. What an amazing accomplishment! I was cheering him on. That is still one of my most vivid memories of him—when he was "normal."

By eighteen months he began to speak. He had a small but useful vocabulary. His voice was music to my ears. He had been meeting all of the developmental milestones. I imagined that before long he would play little league baseball. I could see myself beaming and cheering as he fielded a ball or swiftly ran the bases. I would be there watching as my father had watched me. Then the train went off the track. Things suddenly began to go wrong in June of 1981, when he got sick with a virus. He was cranky and irritable. His pediatrician treated the ear infection that had developed. The infection went away, but my son never got better. He never spoke another word. He stopped playing normally, and began flapping his arms almost all the time. He didn't seem to understand or respond to the words and gestures as he did before. He cried a lot and didn't sleep well at night. That exciting time when every day seemed to bring a new accomplishment was gone. His life and mine have never been the same.

Tariq stopped talking and stopped playing with the toys he had received for his birthday. His little workbench with its nuts and bolts and tools sat idle. My parents had given it to him for his first birthday, and it was just like one I had when I was a little boy. He began playing with a transparent baby rattle with brightly colored beads inside. He seemed fascinated by this toy and played with it for days and weeks on end. He ignored virtually everything but that rattle,

I was tense and anxious, and wondered if I or his mother had done anything to cause his condition. I kept telling myself that everything would be ok. Yet Tariq became very agitated and upset if the rattle was taken away. His life, which had been a constant joy, became a worry. I was glad to see him when I got home from work, but the fun of playing with him was gone. He still liked being touched and cuddled sometimes so I clung desperately to the hope that Tariq would be normal once again.

When he was two, I spent the whole summer with him. I worked to get his attention—to establish eye contact and a connection again. I would put him on the swing in the backyard and stand in front as I pushed him. All the while I tried to catch his gaze for a fraction of a second. He was a master at avoiding me. It was especially frustrating because as a teacher I was skilled at helping children, but all my efforts with my own son had no results.

As his third birthday approached, it was clear that he could not attend regular preschool. He ignored everyone and wouldn't sit still for more than several seconds at a time. He didn't follow directions. He grabbed things from other children, especially foods or toys that attracted him. Now began the trips to numerous specialists and special schools. There were many sleepless nights waiting for various test results. There were no answers, or no one was brave enough or sure enough to break the bad news. One psychologist thought he might be hearing impaired. On his advice I had gone to tour a school for young children with hearing impairments. It was scary to imagine that my child could be deaf.

A specialist found fluid in his ears which blocked his hearing, and he was treated for this condition with medication. My hopes rose as tests of his brain stem indicated that his ears worked, but it was impossible to tell if his brain comprehended the words. The fluid cleared up, but there was still only grunts and babbling and crying—no words and always twisting and turning to get away. Still I dreamed at night that the babbling would turn into words since that's what babbling leads to for the ordinary child.

By age three, Tariq was the most difficult child to manage in his early intervention program. He required one to one attention all the time. He couldn't or wouldn't stay in his seat for more than a few seconds if left unattended. Whenever I wasn't teaching myself, I spent the day with him in school, helping the teachers, but little progress was ever reported.

After two years of early intervention, my boy was diagnosed with autism and mental retardation. He never spoke again and never learned to read or write. He has remained until this day extremely active and unaware of danger. It was confusing and bewildering not knowing which end was up—feeling so badly and yet having an adorable child with a serious “problem.” A grief beyond words, where there was no death, and a severely disabled but normal looking child who I have loved as much as life itself. While the anger has long

ago subsided, the tears are never far.

I remember withdrawing inside myself as I learned about the disorder. It was painful to read that autism was a severely incapacitating and lifelong disability. It was hard to comprehend that my child's brain could not process what he hears, sees, or otherwise senses. The information that he takes in is distorted or fragmented, making it incomplete or confusing. I was told that communication with others or the world outside him would be extremely difficult. In the daytime now I walked around numb, and at night I cried and cried. There was no comfort. Professionals, relatives, and friends rarely seemed to know what to say or how to say it. Like many parents in similar situations, no expense was spared in the quest to find a cure for Tariq. Speech and movement therapies and even vitamins and a special diet were tried to help him. The burden of the debts from these treatments was in itself for years a constant reminder of my hope for a cure. My dreams died a slow death as I ran out of treatments to try.

It's so much easier to tell this story years later in hindsight. Parents of children with disabilities have often bonded with a child who had been a normal healthy infant—as it happened for me. One day we found out that our perfect baby was no more. In some cases the baby was damaged at birth, and our chance to bond normally was stolen by fate. In either event, we lost the baby we thought we had. Then we were faced with understanding what had happened and bonding anew. I can tell you that it took me time—measured in years. As a professional observer, I have learned that this is not unusual.

Although Tariq went through early intervention, he did not catch up as I had desperately hoped. Instead the gap between him and his same aged peers grew wider and wider. Having been trained as a special educator, I certainly understood the federally mandated concept of the “least restrictive environment.” This legal concept is often interpreted to mean that a child with special needs is placed in a regular classroom with the opportunity to interact with typically developing peers whenever possible. If the individual child's needs cannot be met in a regular classroom, then placement may occur in a separate classroom or even a separate specialized school.

I wanted so badly for my child to be included with regular children. I myself wanted to be included with their parents. I was actively refusing to be part of the club of parents with a child with a disability. So at the age of five, I kept him out of the public school system, and enrolled him in a Montessori Preschool hoping to avoid special education classes. After a year he seemed to be making no progress despite private therapies and intense efforts by all involved.

I sought professional help through psychotherapy to understand what I was going through. It was hard to make sense of my feelings. I wanted to reconcile them to the reality I was experiencing. I was being flooded and overwhelmed with emotion, and it felt crazy at times. There was a kaleidoscope of emotion

that intruded into and disrupted my normally optimistic view of life. It included various shades of shock, fear, guilt, anger, shame, and sadness. I couldn't understand why I was unable to calm down.

By 1985, I had become a single parent with joint custody, and Tariq spent half of his time in my household. A colleague who was to become my best friend showed me an article in the then current issue of the *Journal of Counseling and Development*. Written by Milton Seligman, PhD, a professor at the University of Pittsburgh, it talked about the grief experienced by the parents of children with disabilities.

I was a bereaved parent, but I hadn't known it. There it was in black and white. As I read sentence after sentence, I came to an awareness of what had been going on inside me. Suddenly many disconnected feelings and thoughts began to make sense. When I completed the article, I leaned back in my desk chair. My eyes filled with tears as I took a few slow deep breaths, and the thoughts crystallized. My boy was still alive, but a dream had died.

From that day, my life began to change for the better. I had a new lens to analyze my experience. My new self-knowledge helped me in the process of learning to cope with the many problems associated with having a child with a disability. It took time and help from others, but it was hard to ask for and accept so much support.

The real sorrow was not so predictable. The stages don't come in neat little packages. It may hit you when you least expect it. Perhaps your friend's child is turning five and is learning to read; meanwhile, your little one still isn't toilet training. One example which stands out for me was how I would buy Tariq cars and trucks for Christmas, and he would have no interest in them like other boys his age. By his ninth Christmas, I had tried to adjust my expectations, so I bought baby toys with the hope that he would just enjoy them.

I still struggled through some horribly dark moments, but I began to reclaim my life. The friend who showed me that article helped me by encouraging me to talk and by listening without any judgment or expectation to everything I had to say. My relationship with my friend and colleague deepened over years. Eventually we married. Life went on with new dreams.

Tariq continued to be hard to manage at school and at home. He would not sit still. His batteries never seemed to need recharging. It wasn't until he nearly was six years old that I could accept his placement at the Center for Autistic Children. There he was exposed to a developmental approach and I was fortunate to meet Doctor Bert Ruttenberg, a wizened child psychiatrist who has spent the last 45 years working with children with autism. He often jokes about how many grandchildren he has with autism. He and his amazing staff loved my boy like he was their own. They celebrated every little step he made. At

times, I wondered what was wrong with me that I didn't see things the same way. I thought I could never rest until he spoke again.

Accepting that his condition would be lifelong was imponderable. Nonetheless their approach of celebrating what he *could do* made a huge difference. He became a happy child, and I learned to enjoy him and accept him as he was. But the autism which I hated with a vengeance refused to go away. Still he twisted and turned to get away, and preferred to be by himself most of the time except when he wanted you to get something for him.

Every minute of every waking hour was affected—the list of Tariq's special needs seemed endless, and the amount of care required was overwhelming. Since he rarely slept through the night, I was constantly exhausted. My physical and emotional exhaustion actually lasted for years. While he was awake he had to be watched every minute. Knowing no danger and being very active, he was always running around the house, pulling down curtains and pictures, and eating anything in sight or reach that he liked. He remained a toddler, only now in a bigger, faster, and stronger body.

It felt like the family was under siege. The entire house had to be "child-proofed." The refrigerator and the pantry had to be locked, and this restricted the rest of the family. Nothing could be left out. He would eat the toothpaste, for example. He would tear papers and books, and break the glass in picture frames when he knocked them down. Especially affected was my daughter Antoinette, whose life was limited by the measures necessary to provide safety for her brother. Since Tariq knew no boundaries, there was no privacy if someone was getting dressed. If you were in the bathroom and didn't let him in, he might just do it on the floor. Any private moment might have a price you were unwilling to pay.

As a child who knows no danger, my son was a constant threat to run into traffic. The only part of my original dream that came true was that Tariq became a fast runner. Unfortunately, this made for few relaxing moments. Like Houdini, Tariq would eventually get into and out of anything we devised. One of the times he got away was from my locked apartment in the middle of the night. I was terrified at the thought of how I might find him as I ran looking for him with my heart pounding so hard I thought my chest was going to explode. I found him playing happily in the playground a few blocks and a few busy streets away. He looked at me and smiled before looking away. I felt a strange brew of relief, and anger, and love. Not long after this incident, another boy with autism died on the tracks when hit by the train near our home. Some nights I kept watch sleeping outside his bedroom on the floor.

Sometimes a sick baby will keep you up all night. You worry and you check to see that your infant is still breathing. What if your child never got better? What if all the love and the best medical care didn't cure that—but your child

lived? Who would you become? I can tell you that it is a grief like no other. It drove me, with my heart in my mouth, to places I never wanted to go. It felt like my baby died, but the crib was not empty. My dream of a healthy child certainly shattered, but there was no funeral. Perhaps the dream should be grieved in some sort of ritual, but it isn't, for there is no corpse. Parents are expected to be brave and keep a stiff upper lip. The dream cannot be buried or cremated, and so for a long time most parents would only hold on for dear life.

I became totally absorbed as so many parents do in caring for my child with special needs. I loved my child passionately and hoped for a cure or a miracle. When none came, in my dark and private moments, I wished to be freed from the burden. I would try to put on a cheery face to hide my guilt and shame. With love and support, most parents survive and become better people, but this is at a price which staggers the mind and heart. Our life force is strong and resilient, but the longing for the healthy child may last a lifetime.

Often the grief can be for ourselves—that our lives as parents did not turn out as we expected. Our child may be happy and content while we still struggle to let go of the dreams we had—whatever they might have been. We can make new dreams as we learn to accept and enjoy the child we actually have. I have come to realize that this is the struggle of all parents, even those of typical children.

Children with special needs are very lovable, but if the challenges are behavioral, as they were with Tariq, we have to chase them around literally going in circles with our emotions often swirling out of control. If the challenges are medical, parents must care for their children's staggering needs with the fear that every breath could be their last. Simply put, our lovely children are very hard to be with. *But when you love somebody, you love to be with them.* When you don't feel that and you think you should, the guilt can be unbearable. Your heart cracks open, and it takes time to heal.

My son's condition continually drove me places I could never have imagined as an "outsider" to this club of parents who had children like mine. After Tariq's ninth Christmas, I faced the reality that his condition required round the clock care. That year he knocked down the Christmas tree; there were broken ornaments and shards of glass everywhere. In an instant, the festive mood had been vaporized. We were trying to live like a normal family, but it wasn't possible.

I had thought I could handle things better than those parents whose children with severe disabilities were placed in residential schools. In the recesses of my mind, there was a well worn path to blaming others for what I cannot understand. Now my life was teaching me that was not true. Years of disturbed sleep and round the clock vigilance had brought me to the horrible realization that I had reached the end of my rope. Any unsupervised moment could lead to disaster. It could range from bolting towards a busy street to smearing his feces

like an infant to climbing out a window. In hindsight I marvel at how I coped so well for so long. I don't think I could do it again.

Some times are harder than others, and December can be such a month for many people. The holiday season can bring reminders of the grief for what might have been. Images of warm cozy family life fill our heads from Thanksgiving through Chanukah, Christmas, and the New Year. It's a time to be close, to give thanks, and to look forward. It's a time to celebrate the lives of children. Families get together, notice changes—and remember losses.

There is no holiday for you when you have a child with special needs. Your inner resources for coping are never on break. Meanwhile, school is closed, and your child's caretakers are with their families, and you are with your child "24-7." If you can't find any support, you feel terribly alone. Your most painful feelings emerge at a time when the world is celebrating, and you have no respite.

It used to be the case that the parents of children with such severe disabilities were immediately counseled by their physicians to institutionalize their babies. Often times, they were discouraged from bonding with their child. This approach was later shown to be detrimental to parent and child alike. In those days, it was common for parents to place a child in a state institution and never return. Some families were even advised by professionals not to visit their children because that would make it harder. The child disappeared and the abandonment became a shameful family secret.

Currently the pendulum has swung the other way. Parents are routinely expected to care for a child at home regardless of the severity of the situation—irrespective of how it affects each family member. There was a constant emphasis on doing more for Tariq which came from many professionals. This did not help with my guilt or with the "acceptance" that I was supposed to reach. It felt like there must be a defect in me that kept me from accepting my son. Was I a bad person? I cried whenever I was alone. At other times I cried on the inside. The tears often clogged my throat—especially whenever I tried to say the word "autism" out loud.

It is not always possible to care for a child with such involved special needs at home, so some families need other ways for their children's needs to be met. It was my experience that it is hard to find support when this is the case. Placement is still seen by many professionals as it was 40 years ago. Even among parents of children with disabilities, there is opposition to considering such an option for the family. People who keep their children at home are often regarded as better parents. The system and the community tend to tout them as exemplary and look down upon those who make other choices. For this combination of reasons, many parents never hear about other ways that their child may be cared for safely and with dignity.

In fact there are options, and I was fortunate to discover them before I broke. My wife, Cindy, had worked at Bancroft's residential program in New Jersey for children and adults with developmental disabilities. She helped me see through the stereotypes I had read about in the late seventies. At that time, the horrendous conditions at state institutions such as Pennhurst in Pennsylvania and Willowbrook in New York were exposed. The trend to de-institutionalize children and adults with mental illnesses and retardation began—as it should have. Many children and adults with disabilities could in fact do better in community settings.

Still there needed to be humane options for children whose needs could not be met in the home of a typical family. In our area alone, there are several fine private schools with residential facilities such as Bancroft, Devereux, Elwyn, Melmark, the Woods School, etc. The children at these schools come from all walks of life. We are fortunate to have so many nationally known schools in our area. Children come here from many states for the specialized care which is available.

Most children and adults with disabilities do not belong in residential facilities any more than most people who are aging belong in nursing homes. Fern Kupfer, a mother who has been there with her terminally ill child, helps us to understand this in her essay in *Newsweek* on December 13, 1982. Perhaps we all share a fear of what may happen to us if or when we can no longer care for ourselves. As a society, we certainly need subsidies and services for families who choose to care for dependent members of any age in their homes. Likewise we need accessible housing for people with disabilities who can live more independently, as well as good group homes and halfway houses. In addition, we need pediatric day care for medically fragile children. Some children require an educational institution with residential facilities, and as Fern Kupfer wrote, "It shouldn't have to be a dirty word."

One night early in 1988, I was awake with Tariq in the middle of the night. As I tried to rock him back to sleep, he looked so innocent and peaceful as his eyes finally closed. As I looked at him, I thought that *if he could speak and reason*, he would not want me and the rest of the family to spend the rest of our lives in the way we had been living. He knew I loved him, and I knew he loved me back. Everyone who ever sees us together to this day can see that. But he couldn't tell me that it would be okay for him to go to a residential school. I had to wrestle with that alone, and I would have to face myself in the mirror for the rest of my life.

Gradually, we understood that a residential program was actually a less restrictive environment for Tariq. There he could and would be freer to run and play and learn and grow within safe limits. He wouldn't have to be tethered constantly to someone's arm. He wasn't being "put away" and abandoned or forgotten because we could visit him regularly, and he could come home for

overnight visits. If he made progress in that setting, as some children do, he could come back to live at home. If a child needs this level of care, then the family has a right to it, and there is state and federal funding to provide it, so money is not the central issue. Unfortunately, as I was to discover first hand after reaching this painful conclusion, most people will have to fight a legal battle to get this care for their child and a reasonable life for the rest of their family.

Every tear drained out of my heart for months. Having to prove that my baby was damaged enough to deserve this care seemed like torture. Likewise the average parent of a child with special needs must often struggle long and hard to get the best possible services for their child. Without Cindy by my side, without the Center for Autistic Children to support Tariq's needs, and without an attorney, I could never have done it.

There were no witnesses to support the school district's contention that my child did not need this level of care, so the hearing was never held. When the funding for the Devereux Foundation was approved for Tariq through the due process procedures in June of 1988, I packed his clothes and a few toys. It was the hardest thing I have ever had to do. I remember sitting on his bed with my head in my hands. It was a no victory to contemplate the sad reality that my son would not finish growing up under my roof.

Because of his sleep problems, Tariq was assigned to the room right next to the night duty residential counselor. A buzzer would go off if he left his room, and the old converted farmhouse at Devereux's Kanner Center, which housed about 15 other children, was encircled with a six foot fence. Now it was someone else's job to be vigilant at 3 AM—someone who was paid to be awake and who went home to sleep in the morning.

Today, looking back, I have no doubt that it was the best I could have done for Tariq and for all of us who love him. I know that is all any of us could ever do whatever our individual circumstances. This confidence helped me face the guilt and get through to the other side. Tariq has gone on year by year and made slow, steady progress within the expected developmental trajectory for a child diagnosed with autism and severe mental retardation. He has grown up in a safe environment. I have seen him regularly and been involved in all decisions about his care. He remains generally happy and healthy. Not a day goes by that he is not prominent in my thoughts and emotions. He is as much a part of our family as any other member.

As difficult as his life has been, Tariq is one of the best things that ever happened to me. I look back and give thanks. As a professional psychologist for the past twelve years, I try to help other people understand what I wish I never knew. There were many gifts that derived from the suffering.

Most striking in retrospect is how at first I thought I would change Tariq and make him the boy I wanted him to be. I dreamed that I would write a book about it. Instead the book I eventually wrote became the story about how he has changed me. He helped me to become the man I needed to be. This helped me to help others which continually helps me to heal myself and experience value in my life and work. Tariq's gifts to me were not in packages, but they have rather continued to unfold and develop over time. Like a tree, they have sunk roots and grown inside me.

Tariq has taught me the meaning of unconditional love. I have learned to honor his sacred right to be loved for who he is. My attachment to his achievements dissolved over time. This was hard to let go in our world driven by appearances and money. Tariq has made very good progress in the past year. He will probably be able to go to a sheltered workshop in another year. That looked unlikely for a good while. He has become able to sit still and focus for long enough to be productive with routine tasks like stuffing envelopes or sorting things. In these 18 years, I have learned to accept the best he can do, and celebrate that achievement. A spiritual revelation grows from the intrinsic beauty of each and every child's existence even with and perhaps because of such a severe disability. What a priceless lesson he has taught me without words in his silence!

The inevitable juxtaposition of my son with healthy, typical children used to be so painful. I used to wince every time my friend's kids and my nieces and nephews passed a milestone that Tariq would never achieve—like graduations from grade school, high school, or college. Now I can enjoy witnessing their progress.

What Tariq has taught me besides accepting him is to accept myself. I think the challenges in our children radiate inwardly our own sense of being imperfect. I had to accept my own imperfections, warts and all.

By the time he was 9 or 10, I stopped hoping he would talk. It was hard to give that up. But what we all face as parents is some balance of hope and reality. With typical as well as special children, we have to give up a lot of expectations in order to love our child in the moment. You can't enjoy your life if you don't love them in the moment. Some dreams are deferred and some dreams are remade. Tariq and I do run together and that is something I imagined doing with my son. We canoe together, something else I imagined. In those moments there is nothing wrong with him or me.

A recent gift was learning not to hide differences. For years, I would only keep or put into books the pictures of my son looking normal. Finally I have gotten to the point that him flapping his hands and him looking normal, are both him. Both images are okay. He is just as lovable either way. I learned this because photographer Tommie Leonardi thought he was a great subject—as he

was. How wonderful a revelation! A certain degree of shame was shed making me feel lighter.

Tariq continues to teach me to live for myself. He needs me and he counts on me to do that. He cannot help me when I become old and frail. Rather I must assure that his needs are met when I am gone. When I understood that my feelings were my own, I could see reality more clearly. He was and is happy most of the time.

My son with no words has helped me to develop my own unique voice. This is even more magical when I recall how shy I was growing up. I was on the edge of the playground throughout my eight years in elementary school. Today my voice comes through as I practice my profession in various formats such as writing, public speaking, training, and counseling.

Children like mine and others with various special needs are a spiritual catalyst. They challenge and sometimes force us to look at ourselves. They help us to accept our own imperfections and the imperfections of others. In that sense Tariq is not damaged in the least. He is perfect as he is. Along with other children and adults with disabilities, he bears witness to the diversity of the human condition and the resilience of our collective spirit.

I learned we don't have to lie to ourselves. You can grieve. You can complain. You can mourn. You can go on and enjoy life. But you don't have to lie about how hard this can be. If I come back, I won't lie to you, I don't want a kid with autism. I want a son who can talk to me. I have three daughters, and they all talk to me. I love them dearly, and they love him dearly.

Last November when Tariq was twenty, we had a big party for him. What was remarkable is that I woke up a few months earlier and said to my wife, Cindy, his stepmother, "It's his 20th birthday. Let's have a party." He hadn't had a party since he was one which is not something I am proud of. But there were so many milestones unmet, and so many disappointments to absorb. Tariq is a generally happy young man now.

It's hard for me to say that my baby is a young man. I have never stopped wanting to hear the sound of his voice. At twenty years of age, Tariq is still my little boy. He still puts his head on my shoulder. He has brought so many kind-hearted people into my life. Having a child with autism helped me to understand myself and others. It made me a better father to all my children and a better person. The greatest gift so far is the glimpse I have into the human heart. Where it is not who you know or what you know but who you are.

Robert A. Naseef (rnaseef@alternativechoices.com) is the author of *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*.