



A MIRACLE OF THE HEART
A Father and Son's Autism Journey

IN THE BEGINNING

The chronicles in this book began in the spring of 1996 when I was asked to share our story at a Zero to Three Conference. Two years prior, Jacob had been diagnosed with pervasive developmental disorder, autism, at a major child development center in Washington DC. We were told that he would have to be institutionalized. The summary of the report read as follows:

CHILD DEVELOPMENT CENTER EVALUATION SUMMARY

11/4/93

Jacob is a handsome 2 year, 7-month-old boy with mild delays in motor development, significant cognitive delays and significantly delayed and abnormal communication development. His behavior is characterized by aloofness, poor eye contact, poor imitation and difficulty in social engagement. These symptoms are consistent with a diagnosis of Pervasive Developmental Disorder.

I wrote these lines on the day we received Jacob's diagnosis:

In less than one minute, Jake moved from being a child who was a late talker, a child who was fun to be with but idiosyncratic, to a child with a serious disability.

The diagnosis from the child development clinic—Pervasive Developmental Disorder; Not Otherwise Specified (Autism)—was a final devastating blow. But the build-up, the fear, the sense of unknowing was a terrifying and exhausting experience.

| *What are my demons? What pain, what sadness, what rage was
Jake's condition uncovering?*

Each of us has our own demons. At that time, mine was the unresolved grief of my father's death when I was 19. When we learned that we were to have a son after two daughters, the vestiges of that unresolved hurt began to emerge. Thus, accompanying Jacob's birth was an unrecognized but deep alien pain growing within me.

In the days after Jacob's diagnosis, I thought about the Akeda, the Biblical story of the Binding of Isaac (Genesis 22). "How dare God ask Abraham to sacrifice his son Isaac?"

Years later, I wrote in the essay, "The Promised Land," *As I faced the challenges of a child with severe developmental challenges, I thought about my son, the one for whom I had waited so long; my only son, the one that I loved so much. Was he to be sacrificed? How dare God ask this of me?*

In her exploration of the Akeda in *The Murmuring Deep: Reflections on the Biblical Unconscious*, Aviva Zornberg writes of the moment Abraham is asked to sacrifice Isaac: "*He has an untroubled future behind him.*"¹

Earlier in Abraham's journey, God had made this promise to him (Genesis 12:2):

| *"I will make of you a great nation,
And I will bless you;
I will make your name great,
And you shall be a blessing"*

According to the Bible, Abraham waited 100 years for Isaac's birth for that dream to come true. Now it was to be taken from him—his untroubled future was behind him.

¹Zornberg, Avivah Gottlieb. *The Murmuring Deep: Reflections on the Biblical Unconscious* (p. 175). (Function). Kindle Edition.

In retrospect, until the moment when Jacob was diagnosed, I basked in what seemed to be the untroubled future that awaited me. I had a new job, three beautiful children, a home in the suburbs. And while not 100 years, I waited 40 to have a son. As we drove home from the child development center, deep sadness and fear overcame me. It seemed as if my untroubled future was behind me.

Three weeks later, on Saturday, November 27, we found ourselves sitting in the home office of Dr. Stanley Greenspan, and our shared Floortime journey of healing and discovery began. Over the next months and years, with Dr. Greenspan's and his team's guidance, we committed ourselves to the Floortime approach to addressing Jacob's challenges.

Two years later, on the day I was standing on the podium to deliver remarks to the Zero to Three Conference, Jacob was playing in his kindergarten class. He was in a mainstream program and required no additional support. The school educators and administrators had no awareness of his PDD-NOS diagnosis.

Several months later, the text of the speech was published in the Zero to Three Journal². The following year, I was asked to present again. That speech was also well received and published³.

Thirty years later, I now know that the days that awaited me would be far richer and more meaningful than I could have ever imagined. Over the years, I have come to realize that while often difficult and painful, our challenges have opened my eyes to life's blessings or, if you will, to God's blessings.

In my initial speech, I wrote: "It was a stroke of luck that brought us to Dr. Stanley Greenspan." In retrospect, it is hard for me not to see the hand of the Divine in this. I have always been highly engaged in my Jewish faith,

²Raphael, David, "Jacob's Story: A Miracle of the Heart," *Zero to Three. Bulletin of Zero to Three: National Center for Infants, Toddlers, and Families*, April/May 1997, Vol. 17, No. 5

³Raphael, David, Jacob's Story Part II: Each Day is Another Adventure, *Zero to Three. Bulletin of Zero to Three: National Center for Infants, Toddlers, and Families*, October/November 2000, Vol 21, No. 2

but the notion of a God that intercedes in one's life has always been a difficult concept for me. But, perhaps, it wasn't just a "lucky" exchange with a friend, who happened to be having dinner with an early childhood clinician that day, which led us to Dr. Stanley Greenspan. Perhaps it all began before Jacob was born when I was offered a job in Washington DC and moved to Silver Spring—less than an hour's drive to Dr. Greenspan's home office and his entire Floortime treatment team.

One could argue that God's hand was also at work when my wife Jo and I both decided to get our master's degrees in social work and, upon graduation, met at a social work party. I've sometimes said that Jake couldn't have had better parents. Not because we are in any way Ozzie and Harriet, but rather because our social work training enabled us to intuitively recognize the potency of the Floortime approach—and to be good at it. A core doctrine of social work, "start where the client is at" is perfectly aligned with the essential principle of the Floortime approach "follow your child's lead". Jo and I were trained, perhaps built to do this.

These theological contemplations had to wait until Jacob had graduated high school as a Georgia Hope Scholar, spent a gap year in Israel, and then graduated from college with a major in Creative Writing and a minor in Philosophy. Only then was I able to see our extraordinary journey for what it was. Perhaps in those early years we were too busy doing the work while doing everything else that life demanded. Three children at three different schools, two jobs, meals to prepare, snow to shovel, flowers and shrubs to plant... But, looking back, thirty years later, it was all a miracle. As I wrote thirty years ago "Jacob's development is a miracle. It is a participatory miracle." Addressing Jacob's challenges was not something we did in our spare time; it was what framed our time. It was a miracle borne of the efforts of every member of our family, and a team of remarkably skilled and caring clinicians. And our immersion in this miracle elevated and enriched us all.

Over the past 30 years I have periodically chronicled Jacob's development and the impact it had on my family and me. The most recent chapter "Wonder" was written in the winter of 2025.

I began exploring the idea of combining these essays into a book in the spring of 2025. I started by re-reading all the material I had written and thinking through how the book might be organized. One evening, in the summer of 2025, Jacob asked (with great hesitancy) whether he could contribute essays to the book. I was thrilled. We agreed that he would write his own chapter but, additionally, we would discuss each of my essays, transcribe them and include them in the book. Thus, we spent hours in front of the computer having AI transcribe our conversations.

The resulting conversations are rich and textured and Jacob's remarkable capacity for deep symbolic thinking shines through. Without question, though, the deeper value, the deeper meaning was time we spent together, sharing our thoughts, laughing and learning from one another. What began as an opportunity for us to reflect on our shared journey of the last 30 years blossomed into precious opportunities for a father and son to unpack memories and think about what it all means. More broadly, what began with a father desperate to connect with his 2-year-old son has blossomed into a young man and an older one continuing to grow together.

At least once a month we head to a local coffee shop to write. Jacob orders a Chai Latte while a skim milk latte is my drink of choice. We sit across from each other; our MacBook computers open back-to-back as each of us pursues our writing journeys. And when he is not looking, I look up at him with joy and wonder. From making the first connections with a child recently diagnosed with an autism spectrum disorder to sitting in front of our computers and writing about life with all its joys, dramas, and traumas, these times together with my son Jacob have, as much as anything, been a search for myself—or at a minimum for my better self.

In his magnificent book *Far From the Tree*, Andrew Solomon writes: “Life is enriched by difficulty, love is made more acute when it requires exertion⁴.”



From where I sit, this is a very significant understatement.

⁴Solomon, Andrew, *Far From the Tree: Parents, Children, and the Search for Identity*, New York, NY, Scribner, a division of Simon & Schuster, Inc., 2012, p. 43