#### HIGH EXPECTATIONS FOR ALL: THEIR IMPORTANCE AND INFLUENCE





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# A Son, a World: A Mother's Discovery

By Dvorah Ben-Moshe

## Take 1 Questioning and Testing

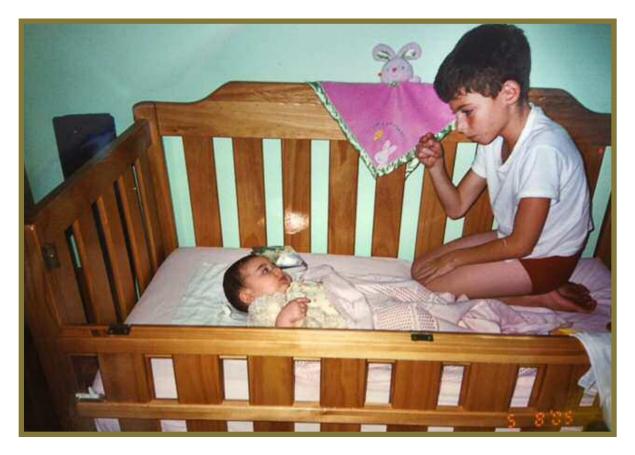
At 2 weeks old, Ilan, our firstborn child, was asleep in his infant swing when his rattle clattered to the tile floor. I expected him to wake up at the sound. When he continued sleeping, I called his dad, Tzahi, into the room. "I think the baby is deaf," I said. Tzahi replied, "So we'll learn sign language." However, we really did not believe our baby was deaf; our comments were in jest.

It was 1995 and we were living on a kibbutz, a community in which much of the life and many of the facilities are shared, in the upper Galilee region of Israel. I worked with the community's youngest children in the infant and toddler house. The job was six days a week, 10 hours a day, so I was familiar with the way babies startle at the smallest sounds. Ilan did not seem to have the startle reflex. I began to wonder if maybe he really was deaf, but I kept my thoughts to myself. We were in a new country, busy with new jobs and a new baby. There was so much to learn and to get used to. Weeks passed and Simcha, the director of the baby house, invited Ilan and me to stay with her for the weekend at her home in the nearby city of Akko. I spoke very little Hebrew, and Simcha spoke no English, yet I marveled at our ability to understand each other. Words, I realized, were just one way to communicate. It seemed an amazing revelation—and this realization would serve me well.

That weekend Simcha noticed that although Ilan was bright and engaged, he did not respond to our voices so she suggested a rudimentary test. Ilan was learning to crawl, and he was eager to tackle the stairs of Simcha's house. Simcha went first, walking backwards and watching him closely as he climbed. I followed. In my hands, I held the lids of pots that we had taken from Simcha's kitchen. I banged the lids together, first to Ilan's right and then to his left, then back to his right—continuing to bang the kitchenware as we climbed the stairs together. Simcha watched Ilan's eyes; they never moved toward the sound. We did this experiment a few more times, and Ilan never looked in the direction of the noise. Simcha was direct: "Ilan cannot hear," she told me.

Photo courtesy of Dvorah Ben-Moshe





"Go home and get him the education he needs. You cannot help him here. You do not have family in Israel, you do not have money or connections here, and you do not speak the language. He'll need you to be his voice until he learns his own language."

In my heart I suspected Simcha was right, but it was so difficult to think about returning to the United States. In fact, this thought felt soul crushing. I had sold everything, bought a one-way ticket, dropped out of graduate school, changed my name, and expected to live and raise a family as an Israeli in Israel. Leaving was beyond my imagination. There were deaf people in Israel, I thought, and besides, perhaps Ilan wasn't deaf.

# Take 2

#### **Deny—and Move on**

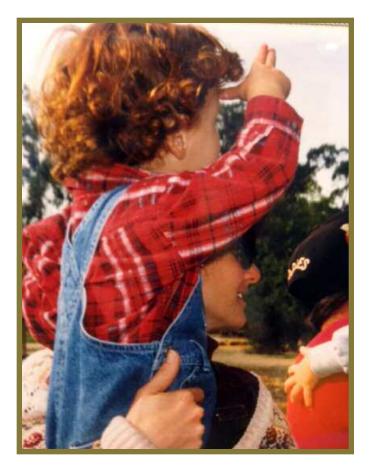
When Ilan was 8 months old, we left the kibbutz to rent a small house in a community settlement. I found work in the town, and Ilan went to the community daycare.

After a few weeks, the director took me aside and asked if we spoke English or Hebrew with Ilan at home. I told her English. I felt she was really asking another question. More gently, she continued, "Perhaps you should consider a hearing test for Ilan."

We made an appointment with our family doctor. The doctor did some simple finger snaps behind Ilan's ears, both left and right. Ilan responded appropriately. The doctor sent us home and told us not to worry. Back at the daycare, the director suggested we take Ilan to Haifa Hospital for a more intensive test. We went, and Ilan was tested. They told us Ilan was not deaf and not to worry.

Three months later, we found a community where we planned to build a house. While the house was under construction, we lived in a tiny caravan nearby. I left the job in town and spent my time at home with Ilan. Ilan's dad worked as a surveyor and was gone from sunrise to sunset six days a week. Ilan and I spent most days hiking in the surrounding area. The more time we spent together in nature, the more I realized we did not talk. Ilan was in a backpack, and I would point to different things along our path: birds, flowers, leaves, rocks, and various animals. Being silent together felt natural until Ilan's dad returned home and I would share with him what we had done, realizing I was using speech for the first time that day.

Ilan was so curious, and he could say one thing clearly: *ima*, which means "mother" in Hebrew. I thought perhaps we didn't speak because we spent all day together so our language was naturally unspoken. Ilan did not babble or imitate sounds yet we communicated; our silent togetherness was full of meaning and connection. Ilan means *tree* in Hebrew.



Ilan even looked like a tiny fall tree with red hair and green eyes. I named him Ilan because I loved trees, and I wanted him to have deep roots, grow strong, and reach for God.

Tzahi was called up for army duty for a month, and I decided to take Ilan to visit my family in southern California. The first week home I made an appointment for a hearing evaluation at the Providence Speech and Hearing Center in Orange, California. On the way to the evaluation, my sister stopped to pick up a few things at a 7-11 store. Alone with Ilan in the car, I turned around and—releasing all my fears and rage screamed into his angelic sleeping face. He did not stir.

The official results were expected: The testing at Providence Speech and Hearing Center confirmed Ilan had a total bilateral hearing loss.

# Take 3 A Step Not Taken

Ilan was the first deaf person I had ever met. I did not know anything about deaf people or the deaf world. My mother, who never wanted me to live in Israel, told me that I must put Ilan's needs first and leave behind my husband, our newly built home, Israel, and my dreams. If I wanted to be a good mother to Ilan, I should stay in California.

Sad, conflicted, and feeling alone, I made a unilateral decision to stay in California and not return to Israel. My family viewed me with pity. My sister said, "Look at you, sleeping on my couch. I thought you'd be the successful one in the family." She was right; I felt like a failure.

I called Tzahi and told him that Ilan was deaf and we were not returning to Israel. He left Israel reluctantly to join us in California. Although Tzahi and I stayed married until Ilan left for school when he was 15 years old, we could not surmount the wall that grew between us; however, we both learned sign language, became involved in the Deaf community, and continued to support Ilan on his journey. Tzahi became an ordained Cantor, and I went to law school.

## Take 4

#### **Discovering Community**

In those pre-Internet days, I began my journey learning about deaf people and the Deaf community with phone calls, meetings, and visits to the library. I visited a Signing Exact English program in Berkeley, California, and learned about cochlear implants. I was impressed and hopeful. Ilan would learn to speak and hear. Perfect!

Just as Ilan was about to start the program, I met a dear friend, Kecia Edge, with whom I had been best friends when we attended the University of Southern California (USC) in Los Angeles. Kecia and I met at a local bookstore. We chatted about our memories of being coxswains on the USC crew team and resident advisors in the same apartment complex. Then I took a deep breath and uttered the words, "My baby is deaf."

Kecia did two key things that forever changed my life—and Ilan's life, too. First, she said, "Ilan is lucky to have you as a mom." Second, she took my hand and led me to the Deaf Studies section of the bookstore and handed me a book. Kecia's kind reaction and the book she handed me changed my fear to curiosity and presented an alternative path to explore. The book was *Seeing Voices* by neurologist Oliver Sacks (1989). Sacks explained the importance of American Sign Language (ASL) for deaf people. I had never considered deafness to be a culture or ASL to be a language. Now my mind and heart were opening to new possibilities. Ilan had a language and a culture. He was not disabled.

### Sacks wrote:

[Looking at deaf people] shows us that much of what is distinctly human in us—our capacities for language, for thought, for communication, and culture—do not develop automatically in us, are not just biological functions, but are, equally, social and historical in origin; that they are a gift—the most wonderful of gifts—from one generation to another.... The existence of a visual language, Sign, and of the striking enhancements of perception and visual intelligence that go with its acquisition, shows us that the brain is rich in potentials we would scarcely have guessed of, shows us the almost unlimited resource of the human organism when it is faced with the new and must adapt. (1989, xii-xiii)



Having resided in Israel, I knew the pain of living where I could not speak the language, read a newspaper, use the phone, or have more than a superficial conversation with the people around me. I had felt isolated, removed from the world. It was different, of course, with Simcha. For some strange reason, spoken words were secondary to Simcha's and my ability to connect, and that ability to communicate deeply without talking extended to Ilan and me. However, I understood Ilan needed a natural language and a world beyond what I could offer. I knew that without sign language, Ilan would be isolated from the hearing world as well as from the deaf world. Without language his very humanity would be denied; he would essentially live in the solitary confinement of his own mind. I made an appointment to visit the California School for the Deaf in Fremont (CSDF), one of the historical state schools where ASL and English are used in a bilingual environment.

## Take 5 Love at First Sign

Hedy Stern, the first deaf adult I ever met, was our tour guide at CSDF. I had never met an interpreter, and I knew nothing of etiquette. Instead of looking at Hedy, I looked at and responded

to the interpreter. Hedy was very forgiving of what I now understand was cultural rudeness. She met me where I was, a mother still beginning the journey that many hearing parents undertake with a deaf child. At 13 months old, Ilan was having his first experience seeing voices. I looked at him and I knew: this was Ilan's language and the deaf people were his people. There was no turning back. Ilan looked up at me in absolute delight. He was happy and engaged. He was finally home.

# Take 6

## Valedictorian and On to College

When Ilan was 3 years old, I decided to learn about disability law. I found a law school in Jacksonville, Florida, near the Florida School for the Deaf and the Blind (FSDB) in St. Augustine, where Ilan's dad had family.

At FSDB, Ilan's kindergarten teacher was Heidi Jordan. I did not know until months later that Jordan was the daughter of Dr. I. King Jordan, the former Gallaudet University president who entered office as a result of the 1988 student protest that brought the university for deaf and hard of hearing students its first deaf president.

Ilan stayed at FSDB for nine years, until we decided to look

for a larger community with a critical mass of deaf students. We settled in Austin, Texas, and Ilan started seventh grade at the Texas School for the Deaf (TSD). In tenth grade, after attending the National Academic Bowl, he decided to attend the Model Secondary School for the Deaf on the Gallaudet University campus. He graduated as valedictorian of his class in the spring of 2014, and in August he began the honors program at Gallaudet University.



# Take 7 Lessons Learned

Ilan is happy, intelligent, and has a healthy sense of identity. As a result of our village, i.e., the many dedicated teachers, loving families, caring coaches, and dear deaf friends we met on our journey, Ilan thrives. We have only gratitude for them.

After 18 years, I am still learning ASL—and making all sorts of errors—but Ilan forgives me, and he knows he is loved and understood. I

am an immigrant parent; I must always build a bridge between the world into which I was born—that of hearing people—and the world in which my son lives—that of deaf people.

Ilan inspires me every day. He begged for a sibling from the time he was small, and his encouragement helped make my dream daughter a reality. Our very sweet Eden, who is another of my great joys, was born in 2005.

My hope for Ilan was and continues to be that he is happy. Being happy, I was surprised to see, was

the theme of his graduation speech. Ilan also talked about power and responsibility, and he ended with the words, "Mom and Dad, you are the real MVPs here today. Thank you for everything. I love you."

Note: Simcha is Hebrew for "happy."

#### Reference

Sacks, O. (1989). Seeing voices. New York: Vintage Books.