

## **Everyone is Someone's Jacob: What I've Learned From My Autistic Son [2007]**

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Four years ago my wife and I endured a difficult pregnancy. She was bedridden from 26 weeks and ultimately required an emergency c-section that delivered our children six weeks premature. They say that it takes a village to raise a child. We know that from firsthand experience, since we would never have survived had it not been for our caring community - congregants who helped us with meals, inquired about Elana and the children's wellbeing, held our hands, and comforted us during a frightening time. When the children were born and the doctors finally let us bring them home, it seemed like a miracle for us and for the entire community. I remember the day that we celebrated Jacob's *brit milah* and Shira's *simhat bat*, how the sanctuary was overflowing with people and food and joy. It was a celebration that everyone had taken part of and that everyone had made possible.

I don't need to detail the hopes that parents have with their children. I don't need to explain how the entire promise of life itself gets concentrated into one little tiny baby lying in a crib; in our case, two very tiny babies. Yet all of the effort and all of the struggle seem insignificant when looking into the pure eyes of those babies and the hope that they embody for the future.

They were beautiful babies, and they developed beautifully. We watched in wonder as they emerged into the world: sitting up at the same time, learning to stand at more or less the same time, even beginning to walk and climb stairs together. Then, somehow, in the second year something changed and our Jacob stopped growing. Our little boy — who had been developing just like his sister — stopped. Shira continued to surge: mastering new challenges, surpassing herself, and delighting in her new abilities. Jacob was still Jacob, but somehow he was pulling away, somehow sliding into some other world, behind some wall that we couldn't penetrate. Our Jacob, who had been so vivacious and so energetic and so enthusiastic, would play by himself for hours, compulsively repeating meaningless motions, endlessly plucking leaves or throwing pebbles, one after another.

His behavior wasn't the only source of distance between us. Jacob's words never came out. He wouldn't talk. It doesn't take a lot of imagination to feel the pain that a parent would endure seeing that. You can understand the delusion that we constructed to fool ourselves into thinking that nothing is wrong, that our boy was just developing differently than his sister, that's all. The horror was so vast that we willingly agreed with the popular pabulum that people offered us: We shouldn't be pressuring him to be like her. We need to let him grow to be who he is. We shouldn't label the boy. And so we repeated to ourselves — our desperate, misguided mantra — until we couldn't honestly say it any longer. Until the reality was so pressing that it shredded our denial. Finally, we took Jacob to a specialist for diagnosis. After a frustrating and futile effort to get Jacob to engage in the diagnostic test, the doctor told us that Jacob suffered from something we had never heard of — PDD, Pervasive Developmental Disorder.

As if this new PDD weren't bad enough, while he was telling us about PDD the doctor kept referring to autism. I felt as though the entire universe had caved in, that we were the living dead. I had been betrayed by God, and the cosmos, and by everything. For months the pain was so great that I couldn't speak about it to anybody. I couldn't share it. I couldn't face it. I couldn't confront it on my own. Jacob, my son, my son!

Since that time, our life has become a battleground. Our home is ground zero in our private war against autism. We are fighting for a beautiful boy who's locked somehow inside himself, who needs to learn how to emerge. Every day is a struggle. The things that other parents don't have to worry about, we worry about. Well-intended opportunities confront us with insurmountable challenges. How can we

accept an invitation to someone's house when Jacob is going to sit by himself the whole time? How are we going to be able to play with other children when Jacob doesn't really know how to play, when he has to be guided, and when the other children have to be taught how to play with him?

How can we bring Jacob to any new place when all new places are frightening? How bring him into a crowd — we live such public lives — when publicity is the very thing that he's most terrified of?

This article is not meant to be just another anguished parent venting in public. I'm sharing this, my pain, because of all of us carry pain, and all of us carry wounds, and all of us bear disappointments. I want to share with you what my Jacob has taught me about life because what he has taught me is precious and applies to us all.

▪ Jacob has taught me to let go of the future. Jacob taught me all the thousands of expectations and impositions that I didn't even know I had and that I had to give up. And I discovered that I counted on them only when I realized I couldn't have them anymore. We tell ourselves, "Oh, our children can grow up to be anything, they can grow up to do anything, they can have whatever life they want to have," and it's nonsense. We don't even know the extent of what we demand of them until they won't do it. And then suddenly we realize how very much we want for them and from them. I now admit that I don't know Jacob's future. Nobody knows Jacob's future. I pray that he will have one that is full and rich. I pray that he will have a good life, but what it is will his to create. Jacob reminded me of something I knew intellectually but he has taught it to me in a deeper way: all we have is today, now. Tomorrow may never be, and it will certainly not be what we expect it to be. So don't postpone joy, or reconciliation, or love until tomorrow. Life is to be lived now, on this day, because this day is what we have and it is all we have. In the words of Israel Zangwill, "for Judaism the center of gravity is here and now. The whole problem of life faces us today". The Sages of the Mishnah counsel "Don't say you will study tomorrow for tomorrow you may not have time. Don't put off righting a wrong until tomorrow, tomorrow may never come." Now, today. "If not now," says Hillel, "then when?" Jacob made me a gift of the present.

▪ The second gift Jacob gave me is that he forced me to reassess what is really important in the world, what it is that really matters in our loved ones. When I first found out that Jacob was autistic, I confess that I experienced fantasies of his dying. I imagined being rid of him, of starting over. I couldn't face the fear and the pain of not knowing whether he would ever come out of his shell. I didn't know if I would hear him speak to me. I didn't know what his future would be. I feared that he would have to endure a lonely old age in which nothing would make sense, his Abba and his Ema would no longer be there for him, no one would appreciate or love him. That nightmare terrifies me still. And so in those first horrible months, I would toy with the idea of his death.

Those daydreams made me realize that the only possibility more terrifying than living with Jacob and his illness is the thought of living without him. His sweetness lights up my soul. When he looks at the Torah and smiles and says "bye-bye Torah" at the end of the Torah Service, something inside me glows. With all of my fear of the future, with all of the suffering and uncertainty his autism entails, Jacob is a blessing as he is. Every child is a blessing as they are. I thank God for Jacob because he is a gift every morning when he crawls into bed with me. Jacob has taught me that what really matters isn't the IQ, although it's nice. It isn't accomplishments, although those are also beautiful. But what's really the core, what we can't give up, what is the essence is soul. What is the essence is sweetness and goodness and loving and caring.

Our worth is not what we do; it is that we are. What is precious is simply that being ourselves, we bring something precious into the world. We don't have to earn God's love, and we don't have to earn each

other's. Each of us is infinitely precious being ourselves and we need to acknowledge that — a gift from my son. The Talmud teaches us “*rachmana leiba'i*,” God wants only the heart. And if we have heart, we have everything and if we don't have heart, no degree, no income, no wealth and fame can compensate for its lack.

▪ Finally, I can see in my son, a beautiful soul, and a *zisen neshomeh* trying to express itself, and I see his sickness trying to shut him in. I see Jacob beating against the limits of his autism, struggling to emerge. I know my Jacob from the inside out, and I know that my Jacob is not his illness. But I also see people shying away from Jacob — confusing his illness for him and not seeing the beautiful boy but seeing instead a label, autism. Jacob isn't autism and Jacob isn't autistic. Jacob is Jacob. And he is like every other child, precious, and sweet, and beautiful if you can learn to address him in a way that he can respond to. It takes effort. It takes starting with Jacob's illness and working toward Jacob's soul, so that his label is a tool, not an obstruction. We live in a world of labels; we live in a world of division. We live in a world that sees only the label and dismisses the person beyond the label. We don't take time to see the person who that label is hiding, who that label is distorting and covering. I have learned that everybody is somebody's Jacob. And every Jacob has parents who, like me, pray that someone out there will be able to see their “Jacob” with love and with compassion. That some kind soul will look beyond the label and will care for their child with kindness and warmth.

We all need to see other people as worthy of our love, not just the ones who are easy to love or to respect, but most particularly those who are not: the nudnik who won't leave you alone, that's somebody's Jacob. The person at work who keeps saying those annoying things, that's somebody's Jacob. The fellow congregant everyone avoids after services, she is somebody's Jacob.

If all we have is the present — and we do —and if everybody is someone's Jacob —and they are — then they deserve your empathy now! Enough with the bickering, enough with discounting each other, enough with ignoring each other's humanity and needs, that time is gone.

My Jacob has taught me more in his 4 years than all of my professors at Harvard or in rabbinical school could ever have hoped to, because my Jacob taught me to live now. He taught me that all that really matters is in the heart. He reminds me to love the unlovable, because the great miracle of life is that if we love the unlovable they become really lovable indeed. And so do we.

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