



# Autism Moms

by Cynthia R. Harp

I had heard of Suzanne long before I met her. She introduced herself one morning when we found ourselves volunteering in the kitchen of the Jewish Day School. “Oh, Suzanne,” I told her. “I know who you are. It’s a small Jewish autistic community.”

And indeed it is. I live in a Jewish community of approximately 10,000, and I have discovered an underground society therein: mothers of special needs kids. Many of us have embraced our Judaism with a traditionalism not seen in our individual family trees in many generations. I am the first woman in my family to go to the mikvah since my great-grandmother went. I began soon after my son’s diagnosis, and I felt both forgiven (as if there were such a thing necessary) and able to forgive—G-d, for making Griffin’s life harder than I wanted for him; myself, for struggling with the concept; and my life up to that point, which had left me woefully unprepared to confront anything more serious than the angst of a grape-jelly stain. My journey had begun, and I, the reluctant traveler began the journey.

After a grueling period of fertility treatment (the irony of which, at age 27 and a marriage of five years, was not lost on me), I had Griffin. Max arrived 13 months later.

When I was able to pull my head out of the toilet after two years of near-constant pregnancy, the most interesting sights were my children. Griffin, however, was undergoing some odd development, or underdevelopment, really. He gradually stopped the cheery chatter and halting first words he had accumulated before Max’s birth. Riddled with guilt and hormones, I watched our sunny toddler

regress so slowly that we were unable to see the full impact. I enrolled Griffin in preschool the following year. His teacher loved Griffin, but was concerned with his lack of speech and social progress. With some reluctance, we had him evaluated, and our odyssey began.

I sat in yet another doctor’s office one day, waiting to hear her prognosis of Griffin. “Now, I work a lot with the Jewish Day School,” she said, mispronouncing the name repeatedly. They must not like her, I thought, or they would have told her how to say the name of the school. I wanted to stop her and say, “Listen, lady. Just tell me if he is f—ing retarded, and while you’re at it, if I am, too.”

My head ached from the effort of helping our son get through pre-school, which was considerably more effort than I had put out into my college career (sorry, Dad).

It was not to be. We were told, very gently and politely and with great compassion, that Griffin could not come back to his pre-school. We got on the carousel of the seven levels of hell that all parents of kids who are “a little different” find themselves taking. In the meantime, both boys went a few days a week to the Lubavitcher summer camp while I hunted down options.

Griffin was assigned a special counselor who took care of only him. He loved camp, she loved him and I loved her. I began to learn with her. As the youngest of 11 and a yeshiva girl, she had a lot to teach me. She went back to New York at the end of the summer, and I wandered into the Partners in Torah study group in my area.

I met Harriet in Torah study. Harriet listened silently while I confided in her about my oldest son. She did not, like so many others had at play group or pediatrician’s offices, tell me about

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her genius children and how they struggled to teach others calculus in kindergarten. She did not say, with false revelation, "Oh, I guess I am lucky that my children have no issues." Instead, she introduced me to her friend Cassia, who became my parent advocate, negotiating the tangle of educational services with me. Together, they formed a human lifeline that led my husband and me to schools and services for Griffin. If saving any one person truly does save a whole world, then what does saving a family accomplish?

The words of thanks are too vast, polysyllabic and choked with gratitude for my family to articulate them. We do the next best thing. We try to help others. Every time I take a call from a worried parent, I feel a rush of love for the universe and the people in it who helped me. If being a parent advocate is taking part in *tikkun olam*, then it is the best part I know.

The teachings of the Jewish texts, the real teachings that aren't gilded in gold with the benefactor's name over the door, teach us: Help each other. Value your children. Teach them to swim, so they may someday save themselves. How could I have ever taken that to be only a literal directive to go to the pool?

## Artists

Dror Mishori ( page 32) and Adi Schwartz (this page) live at Kfar Ofarim, an Israeli residence for autistic children and adults, where Judith Firstater (now retired) was their first painting teacher. Their work is reprinted here, with permission, from the Hebrew picture book for children, *Yesh Li Haver V'Hoo Aher* (I Have a Friend and He Is Different) by Edna Mishori, published by ALUT, the Israeli Society for Autistic Children. [www.alut.org.il](http://www.alut.org.il) The book and its artists have won a prize from the Israel Museum.

Is it a coincidence that I met Harriet and Cassia through the Jewish world? I don't think so. By the kind of good fortune that makes me believe in *hashgacha pratit*, or Divine Providence, I am part of a weekly coffee klatch that is both group therapy and social outlet. One woman tells the story of her older daughter screaming at her youngest daughter to hurry up or they would be late for school. The youngest daughter, Sarah, was the most profoundly deaf child ever to be born in our hospital. Esther knew that as well as anyone else who knew Sarah. But, life rolls on, and school starts on time no matter what your disability.

One mother told us recently that her daughter had had "such an LD moment at Sunday School. The kids were supposed to count as many *mezzuzot* as possible in the synagogue. Her daughter's group came back with the highest number. The teacher commented, 'I didn't know we had that many *mezzuzot*.' The daughter said, "Well, we went to the gift shop." Talk about thinking outside the box!

Of course, the "box" of social comportment has its place. This "place," however, can be decided on a broader scale than most of us were raised to believe. A few years ago, Griffin used the momentary lull in the Torah service one December Saturday morning to shout, "Santa Claus!" Everyone—including the rabbi—laughed for a full minute. A small part of me wanted to stand up and announce at length how we do not celebrate Christmas, nor drink in the morning (although it had appeal to me at that moment). The part of me not part of the small part, however, thought: How cathartic. That needed to be said.

My frustration has since turned to gratitude for G-d and life giving me the amazing gift that is Griffin. Yet, I feel sure that my Judaism, renewed as an adult, is a major component of both how I deal with special needs in the early twenty-first century and how Griffin sees the world.

At the end of an appointment with a Hindu pediatric behavioralist, the doctor turned to me and said, "Have faith in fate." It was a bizarre thing for her to say, in a bizarre setting for her to say it. Yet that was the most helpful, comforting advice I'd heard.

Many in my "underground" society of Jewish-moms-of-special-kids have also renewed their Jewish practices and beliefs. I know several who went from twice-a-year synagogue visitors to traditionalists who learn Torah on Monday nights. I am slowly moving toward the latter, but I was certainly one of the former. We used to stand together at the park on days our Jewish pre-school closed for what were (to us) obscure holidays, trying to figure out what Shavuot was, anyway.

There is no place like the Jewish community for labels. I have had few conversations outside my realm as parent advocate for special needs kids and their families that do not begin, "My son/daughter...is really so advanced..." This sentence used to cause my entire emotional system to either shut down or melt down, depending on how the day had progressed thus far. Now, I focus my energy on not rolling my eyes.

In retrospect, I suppose I was naive not to see the dark side of being part of "the People of the Book." We are blessed to be part of a tradition that sets such value on education. But what if a member of the people of the book can't read the book? Or wants to read it in Braille, or while sitting on the floor of the sanctuary, or run in circles and flap his arms while the rabbi davens?

The upside of labels, of course, is finding our place in the world. I am a mother. Judaism, despite the patriarchal dogma, venerates the mother. I truly believe I am here, right now, right here, to take care of my children. I truly believe in the specificity of that, that I am here to take care of these particular children. There is an old saw—not necessarily a Jewish one—that everyone picks his or her own parents. I used to tell my husband that Griffin chose us because his soul knew we could help him. Now, I truly believe he chose us because he knew he could help us. He has opened my heart in ways I was not aware were possible; he has given me joys I never knew enough to miss.

I would love to say that every parent of a special-needs child I have ever met in the Jewish community is happy, well-adjusted and sitting around the mah jongg table telling amusing anecdotes on their home lives. Alas, I can't. I see suffering souls every day who are both being made to feel and make themselves feel guilt, shame and despair that they have a child with a "problem." I make an effort every week to tell them I am available to talk, advise, cry and lead them gently to those things that will make life bearable.

The hardest part of hearing the diagnosis of autism was that there is no real prognosis. The term autism itself is something of a garbage-can term. There are innumerable characteristics that can be called autistic-like, and if a person is judged to exhibit a certain number of them, they are on the autism-spectrum scale. Kids change rapidly and in unexpected ways. That is true expo-

entially for the special-needs child. So who knows what tomorrow will bring? At my first parent advocate training class, the leader told us: "I know why you are all here. It is the same reason we all are here. We each have at least one kid with special needs. So I know that it can be a beautiful, sunny day and suddenly, all hell can break loose. So I will not tell you to turn off your cell phones."

Until I accepted that understanding, I had a very modern American perspective, I think. I looked forward. I planned: vacations, summer camps, paying for medical school.

Autism forces me into the present. For one thing, as a toddler, Griffin could and did have my mail off the table and shredded into the garbage (or toilet) during the leisurely 60 seconds it took me to walk from the garage to the kitchen. Not only did philosophy force me to be alert to the present, but health, well-being and preservation of mailed checks demanded it.

Judaism helps us stay in the present – that seemingly New Age axiom – through ritual practice and prayer, among other ways. One of my favorite prayers is the *Shehechyanu*. Thank you, G-d, for giving me life, sustaining me, and allowing me to reach this moment of pulling paper towel rolls out of the overflowing toilet. The thanks are real. Being the mother of my boys defines me and forces me to be who I am, and who I have to be. My father once told me, "Those guys who got medals for saving lives on the battlefield, they didn't want to be there. They were drafted to be there, and they decided to do what they could to save somebody." It was the most meaningful comment anyone had made, and the most poignant. In all ways, having Griffin saved me. When I tuck my boys in every night, I tell them that their daddy and I prayed to have babies, and G-d gave us them. G-d gave us the very people we prayed for, exactly who we needed. We mean it.

Going to the mikvah is another way Judaism helps me stay in the present. It is my own personal Rosh Hashanah; it is at least the *rosh* of the month for me. When I am submerged in the water, without any external artifice, I am able to strip away my internal artifice as well. There is something about being down to my most basic element that forces me into the here and now. I do not worry about the grocery list, nor how Griffin will do at his bar mitzvah in five years. I go under, I rise up. I welcome another month. That is all I need to know. And by focusing on what I need to know, each moment, I am able to meet each moment fully.

I am here, and so are the bundles of love, wonder and dirt that are my children. Suburban angst, unsorted laundry and mismatched socks (usually mine) fade away effortlessly when I embrace, literally, the blessing of the details of my life. What more can any religion give us than that? ●

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