

An Awe-some Bar Mitzvah

Special needs does not define a Jewish child becoming an adult

BY MARK AND FRAN KATZENELLENBOGEN

Organizing a Bar or Bat Mitzvah is no easy task. This is especially true if your child has special needs. In our case, Zak was diagnosed with autism at the age of 2, so it has been 11 years of challenges to reach this milestone in his and our lives. Fortunately, he has many abilities that enabled him to participate and enjoy this special occasion.

Being members of a smaller congregation like Brith Shalom helped, as there was less pressure, and the staff was very accommodating. What many people do not seem to know is that all that it takes for a child to become a Bar or Bat Mitzvah, is to reach the age of 13 (or 12 for girls) and be called up to the Torah. Many parents seem bent on trying to do too much, instead of just doing what the child can do or is comfortable doing. Apparently, the Torah states that each child should learn at his/her own level.

We were surprised when we were notified that Zak's date had been assigned, as we had not even begun to think of a Bar Mitzvah. It seemed like a very long time away. We knew that Zak would be able to participate with enough positive encouragement, repetition and patience; lots of patience. Over the next 18 months, he went to weekly tutoring, and in the end, he was able to read in Hebrew all the assigned parts of the Saturday morning prayer book. Zak's shining moment was when he read the Torah blessings, chanted the last portion of his *parashah* from the Torah and ended by singing "Torah, Torah, Torah."

Zak benefited from being at other B'nai Mitzvahs, so he could learn the routine of what would happen and the staff's expectations of him. Modeling is important to all children with special needs. Tell me and I hear it, show me and I learn it. We also included our daughter Zoe in the process. She recited the *Ashrei* and modeled confidence, as she practiced with the cantor, with Zak observing.

Perhaps the only disconcerting issue regarding the Bar Mitzvah experience was Zak's exclusion from many other children's celebrations. Parents need to know that all members of a B'nai Mitzvah class should be invited, so they can be included and learn.

Exclusion exists on many levels, but it should be a common courtesy to include all children who are making this milestone, whether they go to a day school, your Hebrew school or any other private school.

During the customary parent's speech, we shared some highlights about Zak. Fran, his mom, said that as parents, we could provide his schooling, but that it was not our work, but rather his, that made him who he is on this special day and who he will become in the future. None of us knows how hard it is for someone with autism, as most people on the spectrum have difficulty verbally expressing themselves. Zak is not an autistic person. He is a person who happens to live with autism. It does not define who he is. It is just one facet of who he is. Like a diamond, he has many facets. Zak happily participates in many activities and always has a positive attitude.

"*Shoftim*" was the parashah, and Mark, the dad, delivered a modern-day *dvar* Torah interpretation on Zak's behalf. *Shoftim* is the Hebrew word for Judges; the theme was "Justice, Justice You Shall Pursue." Justice is one of the eternal religious obligations of Judaism and seemed to be the perfect portion to convey some ideas about how we treat the weakest in our midst – this is the irreplaceable core of our Jewish identity. The concept implores one not to judge unfairly and states that we should not judge people until we have stood in their shoes. It tells us to "speak up for those who are silent, for the rights of the unfortunate, to speak out, judge justly, champion the poor and the needy." Mark concluded by saying that when the "stigma" of someone having any issue out of what we, the so-called typically developed refer to as a special need, then Justice, Justice shall prevail.

We must add that, even though most people mean well, at the end of the day they can close the door and shut out their good intentions and work, while the parents, siblings and other caregivers cannot. We live with special needs 24 hours a day, seven days a week.

Many of our friends are from Chabad or are Shomer Shabbat and could not attend the Saturday morning service, so on Friday night, our family celebrated Zak's becoming a Bar Mitzvah by sponsoring a dinner at Chabad Outreach. The local Chabad Outreach is extremely active and supportive of children



Zak Katzenellenbogen learns the blessing for putting on tallit.

and young adults with all forms of disabilities. Their Friendship Circle brings together typically developing individuals and those who have special needs to form lasting friendships.

Zak participates in *tikkum olam*. He volunteered delivering meals to those who needed them following Hurricane Ike. For his tzedakah project, he walked in the first-ever Friendship Circle walk, and his team had the highest sponsorship for a child. He made the table decorations, which then were donated to the JCC's Meals on Wheels, and he donated a portion of his Bar Mitzvah gifts to the Friendship Circle, towards their next walk, scheduled for Sunday Feb. 21, 2010.

Shabbat was amazing. What the four of us worked for became a reality. It was moving, meaningful and when Zak declared he was finished – something every typical child thinks, but doesn't share aloud – we knew he understood that he had accomplished what he set out to do. He became a man. At that moment, members of the congregation spontaneously applauded for Zak. We've never heard applause in a sanctuary before, but as several people told us, "it should be called 'awe'-tism as Zak was awesome."

In reality, many children with autism never will even attempt to take on such a huge undertaking, but at our synagogue, Zak has blazed a new trail for anyone who wants to do so. We believe many came to see what our child with special needs could do. In the end, eyes were opened, and people were thinking about abilities, rather than disabilities. For that, we thank Zak.

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