

OUR SPECTRUM

By Dina Wosk

I have twin 14-year-old sons, Sam and Jack. Jack's development is typical; Sam's development began to shift when he was 18 months old. At the time, all the telltale signs were there; but we weren't sure how to read them: Was Sam a late bloomer? Did he need extra time to catch up to his brother?

We were able to get an appointment with a neuropsychologist, and at the age of 21 months, Sam received an autism spectrum diagnosis. The doctor was able to get us into a school, where he began receiving 30 hours a week of early intervention, and he remains a student there to this day.

Raising a child with a disability isn't easy. It can be trying to see one of my twins reach milestones and gain independence, while the other lags behind. It can take a lot to hold back tears through the school plays and sports games, the sleepaway camp drop-offs and sleepovers, when one child can participate and the other isn't able to be there. Many more milestones are on the horizon, and the differences will be clear: Jack will receive his drivers' license; Sam will not be ready. Jack will graduate high school and college; but we're not sure how Sam's education will play out. I'm looking forward to Jack's well-deserved achievements; but, I know they will sting, as Sam won't be by his side.

People who aren't on the spectrum pick up things intrinsically. But for people on the spectrum it's incredibly difficult, and it can take them a lot longer to get tasks done. So, it can take a lot of patience. As a parent, I do a lot of deep breathing, and work on my ability to "roll with it." We do our best, practice Sam's routines over and over and tap into our 'patience bucket.'

Sam is a funny, sweet, kind boy who has an infectious laugh and a smile that melts your heart. He works so hard at school and in his therapies, and you can see that he wants to do things well. But he has communication and social challenges. We celebrate all of his triumphs, large and small. Because when he picks up on something, it's a natural high. It makes my day. I cheer him on and make sure he understands what an amazing job he did. He may work on something for months or years, but then it's like, "Holy cow; you got it!"

And that was definitely the case with our twins' bar mitzvah. One thing my husband and I always wanted was for both our boys was to become bar mitzvah, together. Years ago, when we started thinking about the day, we wondered how it would look because we wanted them to share the spotlight. I don't know how I would have reacted with Jack at the bimah and Sam not.

When I found out about Gateways, it was as if we hit the jackpot. I'm not sure how Sam would have reached this milestone if it wasn't for everyone at Gateways. All I knew is that I was adamant about making *their* b'nei mitzvah happen, because why should Sam have to miss out just because he has autism? I believe that no matter the disability and how profound it may be, becoming a bar/bat mitzvah should be something that every child can do.

Sam worked hard with Gateways and his team to learn the prayers he was able to recite. We were fortunate to have a wonderful rabbi who understands our family dynamic and supported us, gave us extra rehearsal time and wanted this day to be truly special. He said afterwards that this was a service he'll never forget. And on our boys' big day, we had an intimate, family-only service with a huge party that evening. I think everybody shed a tear, except my husband and myself, because we thought, "Why is everybody crying?" It was beautiful day; a great day! Sam did it. They both did it. It was a home run.

This is just a snapshot of my story; but there are thousands more in the news, in articles and online. I'm hopeful this means that people are becoming educated on the disorder, understand and support the value of inclusion.

My husband and I never dreamt we would have this family dynamic. Having a child with autism wasn't "supposed" to be a part of our lives. But I truly believe that things happen for reasons, and there's an answer and blessing in our experience. We may never figure out the "why"; but there is a purpose. And no matter the situation, I try to look at the world as a "glass half full." You have to keep in mind what your child can do—not what they can't—and celebrate them!

Sam continues to make progress with all his objectives and goals, and works year-round to achieve them. In the meantime, my husband and I work toward our ultimate goal of having Sam be as independent as possible when he reaches adulthood. He's working towards that every day. The small moments—such as when he advocates for something, engages in a small conversation or initiates social interactions—are incredibly exciting. But what's most important is that he's happy. His happiness is going to be different than what we may have planned, and that's okay, because we respect that he's his own person on his own path.