Raising the Bar, Maximizing the Mitzvah: Jewish Rites of Passage for Children with Autism

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As an invested cantor from the Hebrew Union College School of Sacred Music, I began working with developmentally challenged youth about ten years ago. Initially they were primarily learning disabled, but over time I worked with children with Tourette’s syndrome and Asperger’s syndrome. I eventually came to focus almost exclusively on children diagnosed with autism.

In the early days of my work I was generally informed by the parents of their child’s diagnosis, not necessarily because I wanted to know, but because anxious parents understandably wanted me to know what I was up against so that I would not have unrealistic expectations as to what their children could achieve Hebraically and Judaically. Given their difficulties with English subjects, including reading, very few of the children had expectations that they would be able to master Hebrew. I certainly did not want to turn the Bar or Bat Mitzvah into yet one more venue in which the children were fearful of judgment or failure. Nor, conversely, did I want to turn it into yet one more venue where the children were essentially given a “free pass”—that is, told overtly or covertly that because of their “shortcomings and deficiencies,” everyone had nothing but the lowest possible expectations for them.

From the very beginning, and long before I had any real mastery of this subject, it was obvious to me that these children were far more capable than the diagnoses would indicate and those around them would expect. This capability was routinely confirmed as one after another demonstrated poise and competence during their Bar and Bat Mitzvah ceremonies, which were truly “off the charts.”

Also from the beginning I could sense the devastating impact of several scarcely noticed but pervasive influences in their lives: constant focus on their shortcomings, coupled with endless feelings of failure based on little more than inability to handle the pressures of the standardized testing that was used to identify, quantify, and ultimately modify those shortcomings; and methodologies that were poorly attuned to apprehending and depicting the true essence of the child but remarkably good at reinforcing feelings of inadequacy and brokenness.

If the spiritually rich potential of this venerable Jewish rite of passage was truly going to be fulfilled, it would need to be an exquisitely crafted
experience that carefully tapped into and strengthened parts of the children that were routinely overlooked, and very likely damaged, by many secular therapies and educational modalities.

To be sure, such transformative potential is an inherent, albeit increasingly unrealized, component of all B’nei Mitzvah ceremonies. But it soon became clear to me that for children who are rarely embraced by the Jewish community, rarely given opportunities to shine and show what they are made of, rarely experience being loved and accepted exactly as they are, this ancient Jewish ritual and the restorative elements it contains could potentially be the single most important experience of their young lives and, by extension, in the lives of their family and community.

That, however, was far from a “given,” not an automatic feature of a special-needs Bar or Bat Mitzvah ceremony. Elevating it to that place would depend heavily on whether the teachers, tutors, and clergy held this as the goal or merely saw it as a one-day event for the special-needs child and those around him or her to feel proud and included.

Make no mistake: if that were all that happened, Dayenu, we would be grateful and sing praises to God for empowering us to provide such an experience. But as we know from the words we sing on Pesach, when we say Dayenu, we are really indicating how grateful we are that God not only took us out of Egypt but also gave us the Torah, the Sabbath, and a whole array of gifts and opportunities that went far beyond any one benefit.

So yes, a one-day event to feel proud and included unquestionably is grounds to sing Dayenu and Hallelyuah, but based on what I observed in the course of bringing dozens of special-needs children to Torah, it is paltry compared to the extraordinary life-affirming and life-transforming potential that this remarkable ceremony, and everything that precedes and follows, can represent to them.

In the beautiful and mystical prayer L’cha Dodi, written by poet and mystic Shlomo Alkabetz in the northern Israeli city of Safed, we encounter this chocha, this bit of wisdom, in the last line of the second verse: Sof Maaseh B’machshava T’chila [The end of the deed lives in the initial thought that creates it].

As applied to this discussion, that wisdom reminds us that the outcome of our efforts will emerge from the intention or the Kavanah that sparked the efforts in the first place. As valuable as this may be, so long as we see the goal of these services as driven by our Jewishly mandated obligation to provide equality and inclusivity, we will be placing considerable limits on the transformative and therapeutic impact on the children, dramatically reducing
Raising the Bar, Maximizing the Mitzvah: Jewish Rites of Passage for Children with Autism

189

the likelihood that the benefits experienced on that extraordinary day will be an ongoing and positive influence in all aspects of their lives.

It seems cruel to lift them up in this way, with little concern as to how to sustain and maximize the experience (and I mean much more than a special-needs post-Bar Mitzvah class). At its core this represents a failure to substantively understand and address the child’s true needs and potential, to embrace Judaism’s real ability to nurture both of these, and to truly recognize our skills as religious leaders to bring all these positives together in a profound and permanent way—the very things the children and their families are hungering for but rarely getting from the outside world.

That this failure so frequently occurs lies, I believe, in how extraordinarily deferential we as a Jewish community have become to anyone and everyone with lots of letters after their name, lots of credentials, lots of bona fides. So when a parent of a special-needs child approaches us, we are inclined to refer them out to the proper “expert,” usually a secular specialist who is truly “qualified” to deal with such things.

But that is not why parents approach us in the first place. They and their children generally have no shortage of such expert influences in their lives. They approach their religious leaders to provide them a vast array of services that are not in their lives: People to love, honor, and accept their children unconditionally. People to provide the pastoral care not found in the doctor’s office. People to bring them beneath the sheltering wings of community that they are so desperately lacking. People to help them vanquish, once and for all, the devastating sense of isolation and exclusion that is a hallmark of special-needs families. The very thing that communities of faith and their leadership are historically well equipped to address, if only we understand our potential to do so not just for the mainstream but for everyone.

That we so regularly fail to do so, that we are so quick to “refer them out,” is, I believe, a reflection of a mindset described in Exodus 13:33, when the spies returned from the land of Canaan to report on the inhabitants there. Upon their return they told their fellow Israelites “as we were grasshoppers in our own eyes, so we were grasshoppers in the eyes of the inhabitants of the land.”

It is inconceivable that a seminary education (particularly one that includes virtually no course material to prepare us for the growing onslaught of special-needs children) might contain the requisite skills to effectively deal with such complex, daunting, and mysterious behaviors—symptoms and syndromes that even the best and most sophisticated medical scientists clearly do not understand.
How could we possibly expect that, equipped with little more than quaint and antiquated Jewish principles and practices, we could provide the core therapeutic benefits that these children and their families need and deserve—and that state-of-the-art clinicians and therapists seem so much better trained to deliver? In the words of Tevye, unheard of, absurd!

This mindset also reaches into the Orthodox community. Consider an article in *Jewish Week* titled “‘Invisible Disability’ Kids Are Being Left Out.” It was written recently by Rabbi Dov Linzer, the rosh hayeshiva and dean of Yeshivat Chovevei Torah Rabbinical School, and his wife Devorah Zlochower, who teaches at Salanter Akiba Riverdale High School (SAR) (and she served as rosh beit midrash and director of full-time studies at Drisha Institute for many years). They are the parents of two children with Autism Spectrum Disorder (ASD).

Their observations are profound and disturbing, particularly as we are almost falling over one another to congratulate ourselves for the wonderfully inclusive services we as a community are providing after years of neglect. An entirely different picture continues to emerge, when we begin to actually talk to the parents of these children, who still feel perennially underserved, misunderstood, and largely unwelcomed by the Jewish community.

Here is some of what Linzer and Zlochower had to say in November 2009:

Why are these disabilities “invisible?” When you see our children and others similarly diagnosed, you think they are “typical” children. These kids are often verbal and sometimes highly articulate; they are of average intelligence and even extremely bright, and their ability to maneuver physically, socially and emotionally in the real world seems unimpaired.

In reality, these kids are dealing with a lot of complex issues. Many of these children find our loud, smelly, busy world overwhelming and may take refuge by shutting the rest of us out. Some seek out even more sensation and have difficulty modulating their voices, sitting still or remaining quiet. Many of them have trouble making and keeping friends despite an often passionate desire to do so. A need for order and control may make the regular, chaotic play of many children unappealing or scary.

More profoundly, these disabilities are invisible because these children have become invisible in our community. Synagogues do not provide Shabbat programming for children who cannot handle the standard Shabbat groups or junior congregation. Day schools do not educate many of these children, and prayer services in synagogue are not welcoming places for these families.
While there have been a number of stories in the Jewish media recently about the rare programs that do exist, more often, families like ours hear that such programs are too expensive and serve too few children to make them viable. We in turn have pulled away from the community in our search to have our children’s needs met.

We send our children to secular schools and camps that serve the special-needs population, we consult with psychologists, psychiatrists and neurologists rather than our rabbis, and we create community with each other, the folks who “get it.” And we convince ourselves that we are doing just fine all by ourselves.

The truth is that we and our children need the support and acceptance of our community. We have asked for help in the past, but we have been told “no” so many times that by now we feel it is futile to ask. And we are angry—angry because our children survive by our advocating for them, and advocacy is not always pretty.

Our synagogues and our Jewish communal institutions need to become safe spaces where we can bring our children, confident that their behavior will be tolerated or, better yet, understood. Our children are entitled to learn and live their Jewish heritage, and they cannot fully do so if they continue to exist at the margins of the Jewish community.1

If these parents, so highly Jewishly educated, so deeply involved in Jewish life and community, feel “referred out,” feel excluded, feel the need to access secular advisors rather than their clergy, it is truly mind-boggling how excluded and disconnected people of far lesser Jewish connection and resources feel.

But whatever the level of Jewish involvement, truly welcoming and inclusive offerings remain few and far between, neither accessible nor affordable for the overwhelming majority of Jewish special-needs children and their families. To the extent that they are offered at all, the programs are marginal extracurricular enrichment programs that pose no challenge to, nor raise any questions about, the predominantly secular regimens that dominate these children’s lives. Nor do they seriously suggest any substantive manner in which our rich Jewish heritage could offer a full-bodied, robust, viable, holistic, and compassionate alternative to a status quo that is increasingly fiscally unsustainable and decreasingly effective in providing true quality of life.

Logically, the Jewish day schools would be the place where this more complete and healing Jewish experience could be provided. But for the most part, the parentally driven need to compete with the best and brightest college preparatory academies in their midst renders them disinclined to admit those who will divert scarce resources or reflect poorly on their record of academic
achievement. It is the inevitable result of replacing quintessentially Jewish values with those of the marketplace.

All of this could easily be dismissed as interesting theory if there was no hard evidence that simple and profound Jewish principles and practices properly applied produce the kind of real-life transformative results described above. But family members describe exactly that outcome, talking about the remarkable increase in scholastic achievement, social skills, and sense of self-confidence directly attributable to the expanded “whole person” approach to their children, that was incorporated in every aspect of the B’nei Mitzvah experience.

Such testimony, coupled with other reports and direct observation, led the sociologist/anthropologist in me to ponder the specific structural elements that were producing such impact, often when nothing else was working.

I was eager to distill and apply these elements in a manner that would maximize such transformative impact for each and every special-needs Bar and Bat Mitzvah child. And perhaps most importantly I wanted to explore how such elements could be woven into a broad range of life-affirming, nurturing, and joyful therapeutic activities in no way limited to one faith tradition, one locale, or one rite.

The B’nei Mitzvah elements I isolated and successfully applied are not rocket science. They are things that we know work, that we routinely demand for ourselves and our neurotypical children, but that we do not routinely offer to children who have been diagnosed with developmental challenges. We obviously, and I believe falsely, believe that their challenges render them sufficiently different from the rest of the human species that they neither need, want, nor are capable of appreciating the basic offerings that we and our typical children simply take for granted. We must also consider that this attitude generates regimens and lifestyles so abnormal, so devoid of a proper balance of mind, body, and spirit, that they produce far more damage than the underlying problems they are designed to address. Rabbi Hillel said do not do unto others that which is hateful to you. Jesus said do unto others as you would have them do unto you. It would seem when it comes to this special-needs population we are heeding little of this ancient wisdom.

ELEMENT 1: RELATIONSHIP

I believe the single most important therapeutic element that must be at the absolute core of every special-needs B’nei Mitzvah is the indispensable and life-sustaining experience of deep, personal relationship. It is the sense of being “gotten” at the deepest level. Social scientists have suggested that the lack of
that experience is as damaging to our emotional and psychological well-being as oxygen deprivation is to the brain. Based on what I have directly observed, children and adults with developmental challenges rarely, if ever, have this experience.

To guarantee that this indispensable ingredient is consistently included and delivered means truly learning what it means to be an “observant Jew”: one like Moshe Rabeinu [Moses, our teacher], who actually noticed that the bush burned unconsumed, while others might have simply walked on, or perhaps worse, in the parlance of modernity, grabbed a garden hose and extinguished the voice of God for the risk that it represented to life and property. It means learning to be an “observant Jew,” empowered to see, celebrate, and support the vast array of interests, gifts, and potential that are part of all human beings, including those with developmental difficulties; it is an inherent part of being created בֵּיתֶלֶם אֱלֹהִים, in God’s image. Things like passion and compassion, enthusiasm and joy, love of music and animals. Things impossible to measure, lying well beyond standardized diagnostic and therapeutic procedure, perhaps more the stuff of art, philosophy, and religion than science, medicine, and psychology, but nonetheless real.

In the words of a sign that hung on the wall of Albert Einstein’s Princeton office, “Not every thing that counts can be counted, not everything that can be counted counts.”

If we honestly examine our own life experience, it is these intangibles, these “unmeasurables,” that make us who we are, that make our lives worth living. We would also likely recall the vital role of a handful of people who believed in, reflected back, and helped nurture these elements, often before we even recognized them ourselves. It is said that faith is the belief in things unseen. In these instances our lives were transformed by someone in our midst “keeping faith” with our very best selves. Doing that requires time, patience, intuition, respect, deep love, and a willingness to persevere beyond external manifestations.

In the normal course of events, none of this is likely to occur once a diagnosis of developmental disability is delivered. The diagnostics focus on shortcomings, not strengths; diagnosticians have neither time nor training to identify these vital intangibles; and the hand-in-glove therapies that emerge are dis-integrative and designed to manage, modify, or medicate each area in which the child fails to measure up. While it is more than possible to impart and improve needed skills from a place of wholeness, it is not possible to arrive at wholeness by addressing in piecemeal fashion a raft of deficiencies. As we learn from the parable of the blind men and the elephant, the whole is always greater than the sum of the parts.
If properly understood and applied, the simple rite of passage of *B’nei Mitzvah* (and its parallel in other traditions) can serve as a powerful and remarkably cost-effective therapeutic antidote to this. This is particularly so if we are astute enough to sort out the therapeutic threads, reweaving them into new tapestries capable of embracing the broadest cross-section of tradition and belief, the widest spectrum of developmental challenges.

**ELEMENT 2: PRIDE OF ACHIEVEMENT**

Because efforts at early intervention tend to focus so heavily on repairing deficiencies, they consistently reinforce feelings of brokenness and offer few opportunities for the children to demonstrate competence and potency outside of the narrowly defined parameters of success inherent to the therapies. Part and parcel of this are inherently lower or different expectations, and more often than not people tend to live up to those standards—be they high or low. Sort of like Goldilocks and the porridge, it is more of an art than a science determining what the appropriate level of achievement should be in terms of the Bar or Bat Mitzvah. Quite frequently, clergy who have minimal training or experience with ASD will suggest the most minimal of accomplishments, like touching the Torah, or saying “Amen” after someone else says the blessings before or after Torah. On the other hand, others will say that if a child can read Torah only from a transliteration (which for many children is in and of itself a huge accomplishment), they are not eligible for Bat/Bar Mitzvah.

To me, the bigger question is how much effort is being invested to explore the individuality of the child, so that the requirements represent not some abstract standard but true growth and authentic accomplishment that can become significant building blocks for feelings of potency to be utilized in far broader real-life circumstances. Part of this entails creatively expanding our thinking beyond the tried-and-true tradition of chanting Torah and reciting blessings, to find ways to incorporate the particular skills and interests of the child into the ceremony. In the case of one of my ASD students, this meant investing enormous time and energy into his musical talents, something that had been grievously overlooked in his secular school settings. When he was allowed to sing and play instruments, he felt the inherent reward of doing something at which he could excel. Having this as part of his Jewish coming of age reinforced positive feelings toward Judaism, and as his grandfather said afterward, it “changed the way everyone in the family will look at him from this point forward.” The grandfather also observed that the extraordinary accomplishment, well beyond everyone’s expectations, was quickly followed by a demonstrable increase in his grandson’s interest in and achievements.
at school. But again this success required sufficient investment in time to ascertain these skills, the resources and inclination to engage these skills, and the creativity to make them an inherent part of the ceremony.

Sometimes the skills are less obvious, less easily incorporated than musical ability, but nonetheless important or accessible. One of my students demonstrated consistent interest and ability in the area of technology. Because his service was not on the Sabbath, there were no concerns about the use of electronics. I decided to encourage this student to create a full multimedia presentation in PowerPoint, which he did with remarkable skill. To do so required his seeking help from other family members when he ran into some of his own limitations, most particularly in finding appropriate resources that would properly elucidate the key themes of his Parasha [Torah portion], which was Shoftim: “Justice, Justice shall you pursue.” So while still maintaining creative control, he engaged with family members in ways that were more positive than had often been the case, most particularly with his older brother. The sense of accomplishment he felt was enormous and immediate, something that he had not previously had a platform to experience and demonstrate. The same creativity that allowed this to occur is another thread that can be distilled from this religious event and woven into a fabric of activities accessible to special-needs children of diverse backgrounds and ability.

ELEMENT 3: MUSIC AND RITUAL

Inherent in virtually all religious and spiritual traditions is sacred music, which is the vehicle and conveyor of generational ethos that goes well beyond the cognitive. Music is certainly a key element of the Bar/Bat Mitzvah rite of passage. Coupled with this religious and spiritual tradition is extensive research demonstrating the musical abilities of ASD children as well as demonstrations of the power of music to calm, heal, and stimulate key neural pathways in children with autism. In his bestselling book, *Musicophilia*, renowned neuroscientist Oliver Sacks further illustrates these points. So the blending of sacred music, text, ritual, and rites of passage into a seminal event presents an extraordinarily rich opportunity to touch and move the ASD child in truly transformational ways.

In one instance, I worked with a child who had little or no consistent speech. I did notice, however, that he joined in group singing, and frequently he could be heard singing the lyrics and melodies on his own. His mother had observed the same thing, but she doubted that he would be able to produce a result on cue or at appropriate times in the service. It turned out
that this musical proclivity was sufficiently strong to enable him to master his prayers and Torah portion in a musical rather than verbal manner, as well as to focus him sufficiently to demonstrate that mastery even in the midst of the distractions inherent in being in front of hundreds of people, many of them strangers. Apparently, the part of his brain that manages music was far more intact than that which manages speech, and I have no doubt that ongoing stimulus of this healthier part could be used to stimulate, heal, and benefit the speech component as well.

The fact that his Torah portion was chanted from a transliteration rather than directly from the Torah in Hebrew was of absolutely no concern to me, considering the remarkable achievement that even this represented in this child’s life and the manner in which it changed the perceptions of those around him (particularly since it is so frequently such limited and limiting perceptions that circumscribe such a child’s existence). This is another clear example how all the elements work in concert. Deep relationship allows us to see the particulars of the child and adjust requirements and standards to those that are both achievable and beyond normal expectations, leading to pride of achievement, which provides ongoing benefit, particularly if built upon down the road. It is what in Hebrew is referred to as Da Lifnei Mi Ata Omeid [Know before whom one stands].

ELEMENT 4: COMMUNITY

Several years ago, National Public Radio aired a show called “The Autism Chronicles,” produced by Dan Collison and Elizabeth Meister for Long Haul Productions, in association with Chicago Public Radio. Perhaps the most poignant moment for me was when one single mother, a devout Catholic and active member of her church, sat alone in the waiting room of a renowned pediatric specialist, about to receive the news about her developmentally delayed son. The diagnosis, though not as bad as she feared, was nonetheless devastating, particularly considering her deteriorating financial circumstances and a second child at home that required her attention. Not surprisingly, she could not conceal her emotions and wept openly in the doctor’s office. He did his best to comfort her, but without a doubt, the minute she left the office she was pretty much on her own. I thought about how many times a day that scenario is played out somewhere in this country and how little support such people receive from religious institutions, whether they are members or not.

I have also seen how this paralyzing sense of isolation is as destructive as the diagnosis itself, not only to the child but also to the entire family structure in which he or she exists. While there have been some excellent efforts to
provide support systems that ameliorate this isolation, they are still few and far between, and for the most part they are secular in nature. Even as synagogues strive to provide more-inclusive opportunities for special-needs religious education, this rarely extends to the worship opportunities or specialized pastoral counseling so desperately needed by the families. Nor does it include opportunities for day school education. For many Jewish families, the special-needs Bar or Bat Mitzvah represents their very first contact with Jewish life, their first experience of being embraced by the Jewish community. If it is handled well, incorporating the entire family rather than just the student, and if it is followed up in comprehensive and substantive ways, this process can be a true win/win situation, dramatically improving lives while drawing in a significant demographic to Jewish life heretofore totally disconnected. But as said before, Sof Maaseh B’machshava T’chila [The end of the deed lives in the initial thought that creates it].

If the focus remains on the student only, on one venue, and on a one-time event, none of this progress is likely to happen. Moreover, if the inclusion rests almost exclusively on secularly oriented educators rather than clergy, the critical piece of pastoral counseling that typical families routinely rely upon and enjoy will not be available to these special-needs families who so desperately need it. Given the various obstacles that such families feel to participation in religious life, extra efforts, more creative experimentation, and more resources will be required to find the right mix that respects the congregational desire for decorum and solace, while not excluding those who might be less able to adapt to such demands. Thus, the catch phrase, sometimes we have to do extraordinary things so ordinary things can happen. For special-needs families, inclusion in religious life would be far from ordinary.

NOTES
1 See “‘Invisible Disability’ Kids Are Being Left Out,” The Jewish Week (9 November 2009); http://www.thejewishweek.com.

FOR FURTHER READING
Shelly Christensen, Jewish Community Guide to Inclusion of People with Disabilities (Minneapolis: Jewish Family and Children’s Services, 2007).