

"Blessed is the Lord our G-d...Creator of a variety of Creations"
(Traditional blessing which is spoken upon encountering a person with disabilities)

Jewish Life Cycle Events:
Including Children With Developmental Difficulties

Stepping up to the Torah, the young teenager looks out at a sanctuary full of family and friends, all waiting eagerly for him to begin. He lifts the pointer to the first Hebrew letters of his assigned portion in the scroll, takes a deep gulp of air, and begins to chant the words and phrases which bind him to a 4,000 year old tradition of Judaism. Today he will become a responsible adult in the eyes of his religious community. Today is his bar mitzvah.

Years of study in English and in Hebrew, learning the history, literature, commandments, holidays and prayers have culminated in this moment. Different Jewish denominations require different degrees of participation in the bar mitzvah service. In some, the child will chant a portion of the Torah (five books of Moses) and Haftarah while in others, the child will lead the entire Sabbath morning service for two to three hours. For all children, it a moment of both terror and exhilaration; for all parents, it is a moment of unbridled pride and joy. However, until fairly recently, children with developmental disabilities were seldom included in preparations for bar or bat mitzvahs.

Along with the baby naming ceremony and marriage, the bar mitzvah ("son of the commandments") or bat mitzvah ("daughter of the commandments") is the best known Jewish life cycle event. When my son Joel, who has autism, was around 10 years old, I confronted the question of whether or not to pursue a bar mitzvah for him. Because of his disability, Joel had only been speaking for a couple of years; why would I want to add the burden of learning prayers in another language as well as expecting him to "perform" before a sanctuary full of people? At that time, no one expected a child with a significant disability to have a bar mitzvah and very little Jewish special education existed. Nonetheless, I wanted a chance to declare Joel's value and dignity before G-d, my family and friends, and the people who had helped Joel fight his way out of the solitude of autism. Luckily, I found a remarkable rabbi and congregation. In May of 1987, Joel stood before over 200 people and recited all of his prayers and Torah portion in English and in Hebrew.

To prepare for a moment like this takes a cooperative effort by both parents and religious educators. In the past 12 years, I've been blessed with the opportunity to help dozens of Jewish families prepare their child who has special needs for his or her bar or bat mitzvah. Together, we've all discovered the amazing degree of determination our children can exhibit as well as the equally amazing degree of flexibility rabbis, cantors and teachers can explore. For every "challenge" a child with a disability presents, there is a creative response:

Cannot learn to read Hebrew: For the child who simply cannot learn to read Hebrew, a language that has a different alphabet and reads from right to left, one option is to write the "script" in transliteration (phonetic English). Another option is to prepare an audio tape with all of the prayers in Hebrew and English. Hours of listening to the tape will help the child memorize the prayers.

Cannot verbalize: Some children cannot verbalize and must "speak" in other ways. Most congregations will accept sign language or augmentative communication devices to express the prayers and Torah portion. One of the most touching bat mitzvahs I attended included a girl who was an elective mute. Eventually, she was comfortable enough with the teacher and cantor to whisper her Torah portion and prayers in Hebrew to them to prove her ability. However, at the bat mitzvah service which she shared with her best friend, she was silent. Unable to speak out loud her interpretation of her Torah portion, she had painted a picture to explain her thoughts. Another very special moment came in a bar mitzvah for a boy who was profoundly multiply disabled and had absolutely no communication skills. He sat on his father's lap, his fingers lovingly curled around the wooden handles of the scroll, as his father chanted the Hebrew in his son's honor.

Cannot stay in one place for long: Recently I read a Canadian news article about a hyperactive, non-verbal boy's bar mitzvah. Knowing the boy might wander the room during the Sabbath service, the rabbi explained to the

congregation, "Today is Ben's day. This entire chapel is his bimah (stage) and he can move in it as he wishes and he can express himself and communicate with G-d in his own way." Another rabbi in Pennsylvania kept a footloose fellow seated right next to him throughout most of the ceremony, explaining that he thought G-d would understand the need to modify this child's obligation to stand for certain prayers. During the services, the rabbi invited the child's best friend to come up and sit beside him. Having his friend who was in a wheelchair beside him both reassured and calmed the bar mitzvah boy.

Cannot be quiet for long: Many parents fear their child with special needs may speak out loudly or inappropriately during services. My rabbi and others tell the "midrash" (story) about the child who cannot speak but impulsively shouts out random letters of the "aleph-bet" (Hebrew alphabet). Angry congregants demanded the child's removal from the sanctuary until the rabbi reminded them, "G-d knows all the letters of the aleph-bet, and He will gather this child's offering and place them in the proper order to form the words of prayer. G-d cherishes this child's prayers as much as any others."

Cannot lift or carry the Torah: Once again, the bar mitzvah service provides an opportunity for family members and precious friends to perform deeds of loving kindness by acting in the child's stead for these and other activities within the service.

These are just a few suggestions for modifying the bar/bat mitzvah to include a child who has a disability. If other obstacles are presented, the parents and religious educators should join forces to adapt parts of the service. While it may not be the traditional approach to a bar/bat mitzvah, making the effort to give this opportunity to a child with special needs will reap tremendous rewards. Every parent who has experienced this event has reported feeling re-connected to their Judaism with an even greater depth of appreciation. All family members and friends who witness the child's performance speak with words of awe and great respect for the child's skills and courage. And, for the child him or herself, being the "bar mitzvah boy (or girl)" means being special... not special as in "special needs," not special as in "special education" ...special as in being the center of attention and acclamation! And every child deserves that.

Published in Disability Solutions Magazine