

How The Religious Community Can Support The Transition To Adulthood: A Parent's Perspective

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Transitions are a universal experience for all of us. Transitions are times of elation and depression, adventure and trepidation. We linger, not quite certain about letting go of what we know before we rush headlong to embrace the unknown. You've experienced this yourself, perhaps when you awaited the arrival of your first child.

I still remember my dreams about my baby's future. They extended just beyond the horizon formed by my burgeoning belly. My husband and I talked constantly about the baby-to-come. Barry wanted a basketball team; he even joked about naming our first born "Meadowlark!" I dreamed about practical things, like, would the baby look like his daddy or his mommy. In fact, one night I had a remarkably clear vision of the baby I was carrying. Being more than a little superstitious, I believed this was a divine message. I awoke and immediately drew a picture of the child nestled in my body. I sketched a drawing of a delicate blonde-haired, blue-eyed baby girl. About a month later, I gave birth to a husky black-haired, brown eyed little boy! So much for the reliability of dreams.

Yes, so much for the reliability of dreams. I learned that lesson quickly as Joel's disability, autism, surfaced at age 21 months. We went from doctor to doctor, therapist to therapist, city to city looking for answers about Joel's condition. It took two years to get a diagnosis...and it was quickly followed by a devastating prognosis: this child will never be anything but profoundly mentally retarded, will never speak, will never acknowledge your existence, will never be toilet trained or feed or dress himself...this child will never be capable of giving or receiving love. If I had any dreams left before that prognosis, they were destroyed at that moment.

But it's not fair to take away parents' dreams! Dreams are what give us the motivation to make it through those scary, difficult transitions. At first, Barry's and my dreams were born of desperation:

- Oh Lord, will this child ever be toilet trained??

- Will he ever sleep for more than two hours a night??

Some were practical:

- Please talk to us, Joel. Please look me directly in the eye and acknowledge that I exist in your world!

And some were silly:

- Oh, Joel, whatever will you do when you grow up??? You have phenomenal math skills, Joel; have you considered going into the stock market?

- You learned to play the piano in just 2 hours; maybe we can find an autistic piano bar to hire you!

But when silliness subsides, we had to seriously consider how to prepare Joel for his transition into the adult world, and we couldn't wait to begin that process at age 18. The first step toward planning the future for a child who has a disability should start very early. It necessitates taking a realistic look at that child: his strengths and his weaknesses, his skills and his behavior. We needed to honestly assess Joel and his finger-flipping, echolalia-spouting, highly vulnerable personality. And from that appraisal, we started to set goals for the future.

Because children with developmental disabilities need extra time to learn things, and because behaviors which become implanted are hard to extinguish and redirect, it's important to lay the foundation early for good adult living skills. For example, Joel had household chores to teach him to respond to directions and also to learn about "cause and effect": empty the trash, set and clear the table, make your bed....and you receive a reward! To make that reward meaningful, it either had to be something Joel wanted or, later when Joel understood delayed gratification, a token that he understood would translate into something he wanted.

It took a long, long time to teach Joel about the concept of money. For children who have cognitive impairments, the concept of currency and wages is too abstract. After all, it appeared to be just a bunch of wrinkled green paper and shiny circles. Ah, but we knew the day Joel finally comprehended the marketplace economy. He had been out spending his allowance with a friend, ran out of money, and came bounding into the house. He rushed up to me, waved his empty wallet in my face and said, "Dollars are all gone -- fill 'er up, Mommy!" Children's chores are the earliest forms of vocational training, and allowances are the introduction to a paycheck.

Joel loves a schedule, and we used one at home and at school. Because Joel was fixated on numbers and letters, he learned the concept of time at a very early age. His teachers and I discovered that we could alleviate his anxiety about the uncertainty of his life by giving Joel a daily, written schedule. It reassured him that there was a pattern to his daily routine, and children with autism are comforted by repetition in their lives. Joel was more flexible than some, and we could alter his schedule, as long as we did it in front of him, crossing out what was deleted and writing in what was added. Remember the scenes in Rainman where the Dustin Hoffman character reminds everyone that "it's 5 minutes to Wapner!" Learning to follow a schedule from an early age established a pattern which Joel continues to use in his job today. His work assignments are in half-hour blocks and are posted on a daily worksheet for him to read. Of course, he also reads and monitors every other person's schedule and has been known to loudly announce anyone's deviation from the posted schedule! Using a schedule, though it may seem rigid and stultifying for some, provides the structure for adult responsibilities in the work place as well as developing a social calendar for some people who have cognitive impairments.

Another essential early lesson was teaching Joel how and when to seek help. Many parents focus so completely on teaching their child who has a disability to be fully independent that they sometimes miss an important point. Those children may feel it is announcing failure or defeat to seek assistance, when it is actually quite appropriate to request help sometimes. There are also times in the adult world when insisting "I can do it myself!" is counterproductive. Employers need to see in potential employees the ability to work as a team. As adults, in jobs or out in the community, they will need to learn how to evaluate situations and determine when asking for help is the best solution. Joel has profound communication difficulties, and this has created the need for the library staff to accommodate his needs sometimes. For example, when he needs help in sorting a particular book, Joel tends to take the library book in question and just aim it in the direction of a librarian. Everyone is working hard on teaching him to verbalize his request for help. About two weeks ago, while Joel was shelving books in the public area, he was muttering to himself, in true autistic fashion. A library patron told Joel to "shut up!" but Joel did not realize the man was

addressing him. The man got angry and screamed at Joel to "Shut up!" in more vulgar terms. By the time this man was hovering over Joel and shouting at him, the library staff intervened. When the patron was informed that Joel was a disabled employee and didn't understand what the man was saying to him, the man said, "They shouldn't let those people out of their institutions. They should keep 'em locked up...they're disgusting!" The good news is, Joel didn't understand THAT either. From this experience, we realized Joel still needs to learn how to recognize potentially dangerous situations and to seek help.

While there are many more ways to teach children how to prepare for the adult world of work and play, the most important lesson may be learning how to interact with those around you. More jobs are lost by people who are disabled because they act inappropriately in the lunch room than for any other reason. Joel does not chat with his co-workers in the employee lounge, but neither does he manifest the rocking, chattering, self-stimming behaviors that might stigmatize him as different, disabled. During these times of relaxation, undistracted by their library tasks, Joel's co-workers might find his "differences" more alarming and unsettling.

How can the Jewish community provide support and assistance to the families of a child with disabilities as they move toward transition?

In our day schools and supplemental schools, we can build a warm and accepting place for each and every child. Our schools become microcosms of society in general, a training ground in which to learn the kinds of skills I've just described. In an academic setting where ethical behavior, "gemilut chasidim" (deeds of loving kindness) and "tikkun olam" (healing the world) are part of the curriculum, teachers can guide all the students through lessons such as when to help someone and when to enable someone to help himself. Challenging social situations can be constructed and appropriate responses modeled for group discussion. Students who have mental or physical impairments can learn to advocate for themselves in a safe environment; their peers provide the best role models as well as influential counselors to impress upon them the importance of issues like shared responsibility, promptness, attention to detail, setting and reaching goals. Teachers can learn how to include systems of tasks and rewards in a child's curriculum as well as providing opportunities for students with special needs to learn how to make choices, all skills which will be used in adult life on a daily basis.

Our Jewish community centers, camps, youth groups and social clubs provide an additional opportunity to prepare for life among the unimpaired. In all of these settings, the essential ingredient is "reality." Children and teens with disabilities need to learn how to manage in the fast-paced world of typical people, a world which won't always slow down to accommodate them. When my agency placed a boy named Gary who has Prader-Willi syndrome in summer camp, we knew his condition included obsessive eating. We used the camp setting to teach Gary, away from home and school, the consequences of grabbing other people's lunches or snacks and how to work on his own behavior in a new, different setting. For Sammy and Dina, both children who are deaf, our camp counselors were instructed to fade away from being the children's ever-present interpreters as soon as possible. Camp became a training site for them to develop communication skills outside the protected, insular bubble of special schools. And for Leah, who has Down Syndrome, and Ari, who has been blind since birth, participation in synagogue youth groups meant learning to employ

self-advocacy techniques on a frequent basis.

The Jewish social service agencies must offer workshops and supports systems for families and teens-about-to-become-adults long before the safety-net of the public school years falls away. Those agencies should offer support groups for the individual who has a disability and for family members; mentoring programs for experienced parents to assist those who are just learning how the system works; social skills training for teens and adults with special needs; and informative workshops on issues which are relevant to those who are disabled. I am amazed at how many parents are uninformed and unprepared to apply for SSI, consider the pros and cons of guardianship and tackle the Byzantine rules of government programs and entitlements. Every Jewish Family and Childrens Service in the country should have at least one social worker on staff who can help a family work their way through these issues.

And finally, our congregations can assist families in the most important way. If a child with a disability becomes an active and frequent participant in Shabbat and holiday services, he will develop a sense of belonging that will carry through for every year of his life. Joel's preparation for his bar mitzvah became a congregational project, and today, ten years later, the congregants still describe his bar mitzvah as one of Temple Chai's proudest moments. When Joel attends services, he is greeted warmly by a significant portion of those attending. The congregants tell me they feel their brief interaction with Joel brings a special blessing to their Shabbat. And when Joel volunteers in the synagogue library or stuffing envelopes for a mailing, he is treated just like every other adult in the group. Joel knows that Temple Chai is a second home, a "safe place" where his participation is valued, and he never questions the appropriateness of his being there. During the period of transition from school to adulthood, when all that is familiar and comforting is taken away from a young adult, being able to return to the security and regimen of weekly prayer and participation in synagogue activities becomes the reassuring anchor during this tumultuous period. Attending services and being greeted by fellow congregants reminds this young adult that he is still respected and valued in his community.

Barry and I have been lucky. Joel made remarkable progress and we were able to dream again, as Joel made successful transitions from private school to public school, elementary grades to high school, self-contained classes to inclusion. And Joel has already made his first transition to the adult world. At age 23, he works full time at the county library, earning a paycheck and paying taxes just like you and me. He has the respect and affection of his co-workers at the library, and he is treated with dignity. Joel has more transitions ahead, when we find a place for him to live outside our home. But, having proven wrong those experts who predicted Joel would never be a capable, responsible person, we continue to dream our dreams, and help Joel become the very special young man he is.