

I am a clinical psychologist and the mother of a 26 year old daughter and a 14 year old son. My daughter has a diagnosis on the autistic spectrum and lives independently, with supports, in a community of adults with developmental disabilities. My son is in 8th grade at the Rodeph Sholom School in NYC. Recently, I was visiting my daughter and we drove by a Dollar Store near her home. “Look Mom”, she called out brightly, “there’s the store that I told you about that Thomas and I walked to the other day! It *only* took us an hour!” When I pointed out, slightly perplexed, that the store was just *two blocks* from her home, she cheerily replied, “Not the way *we* went!”

I share this story not only to give you a sense of my daughter’s charm and good cheer, but also because my own path to active involvement in the life of my synagogue has gone something like my daughter’s recent trip to the store. Though I come from a Jewish family, my upbringing did not include much meaningful participation in the spiritual aspects of Judaism, and most people who know me would not necessarily expect to find me here—part of a presentation at the URJ Biennial. But it has been through my work with our synagogue’s Special Needs Committee that I have found a place within my Jewish community.

Gina Levine has described the formation of our Special Needs Task Force at Congregation Rodeph Sholom in New York City, and the process we went through in creating services specifically designed for families who have children with disabilities. I am going to tell you about my own round-about journey to the synagogue half a block from my home. Then I will describe some of the challenges faced by families with special needs, and finally I will share with you some empirical findings regarding spirituality and disability.

Some years ago, after my son was enrolled in the Rodeph Sholom School and our family had joined Congregation Rodeph Sholom, I called the synagogue, looking for activities for my daughter while she was living at home for the summer. We live around the corner from the synagogue, so the proximity was a huge plus for someone who wasn’t yet able cross streets or

travel unaccompanied. I was desperate to create a supportive structure for my daughter while she was away from her regular school for the summer. It can be an extraordinarily daunting proposition to develop a safe and meaningful agenda for an energetic though highly dependent teenager. Although this was only about 10 years ago, there was absolutely nothing in our neighborhood for a teen on the spectrum—not a class at the JCC, and not an hour or two per week of supervised volunteer work at our synagogue. How could I consider myself part of a synagogue community when there was something there for all of us *except* my daughter?

As a young child, she had been keenly interested in Judaism. We celebrated the major holidays, usually with friends, but we didn't belong to a synagogue. When she turned 16 or 17, my daughter began to talk about converting to another religion. We had chosen a Jewish school for our son for a number of reasons, including our desire for him to feel more secure in his Jewish identity than my husband, my daughter or I had felt. We began lighting candles on Friday nights. I took Hebrew classes. We attended services where, at moments, I would feel an achy kind of longing alongside a feeling of being an outsider. Try as I might, I couldn't quite find a way *in*.

Preparing for this presentation, I came to a new understanding about something my daughter's first grade teacher reported to me many years ago. One day, when I arrived for pick up, she told me that my daughter had come off of the school bus that morning saying, over and over; "I'm losin' my religion." Some of you may recognize "Losin' My Religion" as the title of a then popular song by the rock group R-E-M. It wasn't until a few weeks ago as I began to put my thoughts together for this presentation that it occurred to me what that communication might have foreshadowed. Without the connection to a synagogue, and regular, consistent participation in a Jewish community, it was hard for my daughter to hold onto her sense of herself as Jewish. (Back to the song title for a moment—like many children on the autistic spectrum, my daughter's language development was arduous and atypical. Early on, we communicated through song. Later, my daughter relied on what speech therapists call "delayed echolalia." She would memorize scraps or chunks of phrases she had heard on

television or in songs or books we read her, and script them together in a very purposeful way, repeating them over and over to try to communicate with others.)

Families who have children with disabilities often become deeply isolated. To quote a participant in a study on disability and spirituality, "...disability can isolate the hell out of you..." (p. 9, 2007, Boswell, Hamer, Knight, Glacoff & McCesney). Life on the autistic spectrum in particular, can make it extremely challenging for families just to accomplish the small, commonplace tasks of everyday life. Grocery shopping, a trip to the bank, taking a bus, eating in a restaurant, going to a movie, visiting grandparents...all of these ordinary interactions with the world are filled with a special kind of peril for the family of a child with autism because these children have tremendous difficulty organizing sensory input for use in daily life (2003, Kranowitz).

Results of a study looking at the stress levels of parents of children with disabilities found, not surprisingly, that the greater the child's behavior problems, the higher the parents' stress levels (Hastings, 2007). When your child's sensory processing is not smooth, as is typical with autism, he or she experiences a kind of anxiety that is unimaginable for most of us. In an effort to deal with a world that is experienced as chaotic, unpredictable and at times even assaultive due to hyper-sensitivities to sound, to visual, tactile and kinesthetic input, children become highly rigid. They cling to sameness to create a sense of order and predictability. The terror they can experience in the absence of routine leads to all kinds of behavior problems in an attempt to cope. You never know when your child might be set off by some identifiable or unidentifiable trigger and begin panicking or tantruming. The tantrums of a child on the spectrum can last hours. My daughter used to go to pieces and tear her clothes off if she noticed a spot on something she was wearing. Her hearing was so sensitive that the sound of a blender or a hand dryer in a restroom was agony for her. A child may bolt out into the street or get lost if you turn your attention away for even a moment. Public restrooms present uniquely frightening hazards as children become too old to accompany the opposite sex parent into the

men's or ladies' room. And from what many families who have come to worship at our Special Needs Services have told us, going to temple is nearly impossible.

This is why, in developing our services, we thought carefully about every element—from the music, to the length of the service, to the kinds of instruments we use, to the sequence of events. In a few minutes, you will see part of a service that is heavily musical, divided into short segments, includes opportunities for interaction, plenty of repetition, and preparation, both before, (through a social story), and during the service, through the rabbi's communications as well as the visual schedule. We've chosen all of the pieces to build in consistency and predictability, and so as not to overwhelm children's processing abilities.

The most recent studies by the Centers for Disease Control estimate that on average, one out of 110 children in the United States is now diagnosed with an autistic spectrum disorder (2006). The reasons for this increase aren't well understood, and are beyond the scope of this presentation, but the numbers of families with family members who have this type of disability alone could fill many synagogues. Yet, when our Task Force explored worship opportunities in the United States designed specifically for people with disabilities, we found almost nothing. This really surprised me. It's so at odds with the Jewish values of inclusion, tolerance, and support for struggling families.

We know that in order to thrive, all human beings need community and a sense of belonging. This need is pushed to a new level for families who have children with disabilities. Their lives are often very circumscribed and strained due to the added challenges they face daily. For many, "just getting up and getting through the day is a full time job." (p. 11, 2007, Boswell, et al). Families are often exhausted, embarrassed, and profoundly misunderstood by well-intentioned relatives and impatient strangers who mistake a child with a disability for one who is "spoiled", or who reproachfully misattribute intense or unusual behavior on the part of a child, to "bad parenting". A sense of disconnectedness from others, the world, and to a greater power has been found as a theme in the lives of people with disabilities (2005, Schulz).

Self-acceptance, positive self-esteem, finding the determination to try to rise above limitations, and a vision of one-self as someone capable of contributing to a community require

a holistic conception of self that is broader than the traditional medical view typically associated with disability. We need a view that encompasses self, spirit and society (1997, Byrd & Fitzgerald in Boswell, Knight, Hamer & McCesney, 2001). When asked why some people with disabilities are able to accept the disability while others “.....fight the whole time and are angry and negative...”, a woman with disabilities replied: “What’s the difference? [Spirituality] is the “spark that sets us apart.” (p. 5, 2001, Boswell, et. al)

In looking at definitions, the psychoanalyst in me was struck by the parallels between the definition of spirituality and what, from a psychoanalytic perspective, makes life meaningful, balanced and gratifying. “Experiencing a meaningful connection to our core selves, other humans, the world and/or a greater power as expressed through our reflections, narratives and actions.” (p. 57, 2005, Schulz). This definition of spirituality comes pretty close to a psychoanalytic conception of mental health, and establishing these connections is something all humans struggle to do.

Research, too, points to an intimate connection between spirituality, and positive coping with a disability, as well as with the losses and the deep suffering associated with disabilities for individuals as well as for their families (2007, Boswell, Hamer, Knight, Glacoff & McChesney). In studies examining the lives of people with disabilities, spirituality has been associated with:

- transcending disability-associated challenges and losses (Specht, King, Willoughby, Brown & Smith, 2005; Nosek & Hughes, 2001; Do Rozaia, 1997).

- becoming a contributing member of a community (2007, Boswell et al).

- fostering hope; a sense of personal control; positive social supports; meaningful engagement in life; a sense of belonging, achievement and self understanding; acceptance; perseverance; determination; resiliency; and new discoveries about the self. (Specht, et al, 2005; Do Rozaria, 1997).

We should bottle it, right? However, the situation is a bit more complicated. You may have noticed that through-out this presentation, I have spoken about “spirituality” and not “religion”. This is because, unfortunately, organized religion, is frequently experienced as a source of frustration for people with disabilities (Boswell, et al, 2007). Some researchers exploring the blocks to spiritual development in this community have even gone so far as to

caution that religion may serve as “...a form of oppression...” that limits spiritual expression. (1997, Fitzgerald in Boswell et al, 2007). In fact, churches and synagogues have been portrayed as places of *limited understanding* of disability (2007, Boswell, et al). This is a phenomenon we desperately need to address, and it is the reason that our Special Needs Committee came to be.

I can tell you from first-hand experience that the kinds of connections that can be built between a family or an individual and the larger world through opportunities for worship and involvement in a synagogue community hold tremendous potential for the renewal of spirit. In the words of one mother who attends our services with her son:

Friday was the very first time I'd taken my son to a synagogue since he was about two years old. It felt wonderful to have him be a part of it...sitting in your shul on Friday gave me renewed hope that there is a place for my son in Judaism, and there is a way to get from here to there, even if I can't see it yet. So I thank you, not only for the services but for the hope you gave me for my son's Jewish identity.

Of the families who come to our Special Needs services, most are unaffiliated. A fellow synagogue in our community, inspired by our model, recently held their first Special Needs service on a Saturday in October that happened to coincide with an early and very treacherous snow storm in New York. Despite the winter weather warnings, downed trees and power outages, the service was absolutely packed. Families travelled from near and far. This tells you something about the hunger for these opportunities.

In closing, I'd like to share two anecdotes with you from our family's experience. We all attend the Special Needs services with my son and daughter serving as volunteers. These are by far and away our favorite services. During the meeting to prepare volunteers prior to the first Special Needs Service, my daughter made an observation. She noticed that the large, colorful schedule posted up front outlining the order of the service was not in the correct sequence. At that time, the schedule consisted primarily of a list of Hebrew song and prayer titles, and she does not speak a lick of Hebrew, so we were all a little mystified as to how she caught this mistake.

A few weeks later as we walked around the neighborhood, we bumped into a friend we hadn't seen in a while—a young woman who had worked as a companion for my daughter several summers ago. The first thing my daughter talked about as we caught up with this friend was the Special Needs Service. When I suggested she describe catching the mistake in the schedule, she said, rather exasperatedly, (with the requisite accompanying eye roll), “Oh Mom. You tell.”

“How did you know the schedule was out of order?” was the surprised reply from our friend. My daughter smiled shyly and then with visible pride and delight covered over with all the casualness she could muster, said: “Oh I don't know. That's just something I'm good at I guess.”

These words brought unexpected tears to my eyes. Just an hour earlier she had been absolutely bereft about not being able to do something independently on the computer, which led to her recitation of a litany of frustrations, from not being able to braid hair to knowing she will never drive a car. Yet, she was an integral part of the Special Needs Service. It was obvious to everyone, and most importantly to my daughter that she made an important contribution. For the first time, she felt not only a part of the Rodeph Sholom community, she felt *needed*.

During our second Special Needs Service celebrating Chanukah last year, Rabbi Spratt and Louie led the congregation in “The Driedel Song”. This was one of a trillion songs I had sung to my daughter as a small child. As the song came to a close, my daughter, who is very particular about details, immediately called out that the song wasn't finished; a verse had been left out. Without skipping a beat, Rabbi Spratt invited her up to the bema (where I might add, she was already headed) and where she enthusiastically sang out, a Capella, the forgotten verse. How fitting, that one of those whom Rabbi Levine referred to earlier as a hidden or forgotten Jew, recovered the forgotten lyrics.

The gift given my daughter of an accepting environment where she can share her strengths has been a gift to me, to our family, and I think, ultimately to Congregation Rodeph Sholom. All in all, I guess it has taken me significantly longer to find my way to the synagogue around the corner than it took my daughter, but for both of us, it has been well worth it.

Thank you.

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