

Inclusion in the Jewish Community

By Miriam Greenspan

Thank you all for this opportunity to speak about Inclusion, a subject near and dear to my heart.

Having just heard her speak, I think you can see how Esther embodies what inclusion is all about. Her ability to give a public talk, the fact that she has the confidence that you would want to listen to her, and that she has something important to say—this is the product of her being included in the Jewish community, and in other communities, and being given the opportunity to be someone who doesn't just receive, but who gives back.

A friend of mine has a child with an unnamed neurological disability somewhat similar to Esther's. She was visited for an extended period of time by a sister who described the family's life this way: *"I see now how your life resembles one of those faery tales in which the heroine is expected to do some impossible task, like weaving gold from straw or counting all the sand on the beach. In the end, she does the task, but only with some magical intervention."*

This reminded me a dream I had when Esther was young, in which our family's impossible task is to clean up and straighten out the world. Piece by piece, we are picking up the earth—myself, my husband, and Esther's sister—and shaking it out like a rug, then laying it out flat. We are working to make the world safe for Esther. If the terrain is flat and clear, she will not stumble and fall. There is a hole in the earth, wide and deep, and Esther is perched on a fragile scaffolding above the gaping abyss. Roger, Anna and I are in place around her, radiating our

attention towards her, barely breathing so as not to disturb the scaffolding, which is a hair's breath away from collapsing. We're moving in slowly, to catch Esther before she falls. Just then, the scaffolding breaks and she starts her fall, as we look on, our mouths open in fear.

Then, as in a living Chagall painting, Esther is lifted up by an invisible force. She magically floats on the air and lands on firm ground. It's a miracle! I run to her, delirious with joy, pick her up and swing her in my arms. Her face is radiant with a rapturous smile. "*Mommy!*" she cries, "*I've landed on my own two feet!*"

All families with special needs would get this dream. There is a vulnerability and precariousness to our lives, and an aching need to make the world safe for the one we love. We know what it's like to be perched or see our children perched on a fragile scaffolding. And we also know the joy and magic of those moments when it all seems to be collapsing, when everything looks quite impossible, and then, amazingly, an unseen force guides us to firm ground.

That force is what has allowed and continues to allow Esther to land on her feet, again and again. It is the force that some of us call God. And it is also the force of community. I've felt the force of the Divine at work again and again in the 29 years of Esther's life in small and large miracles. I've felt it whenever human hands—the hands of Rabbis, of doctors, of therapists, of friends, of family, of those who work with people with disabilities, of people who care—are extended to her, and to us, and we are lifted up.

All of us, like Esther, are lifted up by Community. Strengthening community is what inclusion is all about.

When we started out as a family at Temple Israel, my reason for choosing this temple was that it was one of the few that offered community to families with special needs. At the time we joined, in 1992, it was unusual for a temple to have a Special Needs Coordinator and to make accommodations, including tutors and one on one aides, for special needs students. The education that Esther received at Temple Israel was due largely to the inspiration and ongoing leadership of Rabbi Ronne Friedman.

In a recent High Holiday sermon, Rabbi Friedman called Esther “the heart of the Temple.” She is everything that a Rabbi would want in a member: actively engaged in Jewish life and in the life of the Temple, someone who has been deeply touched by Jewish teachings, who is devoted to ongoing education, and who has her own unique and often profound contributions to make to Torah study.

At a Torah study around the High Holidays, the question came up: Who’s a better Jew, a Conservative or a Reform Jew? Esther raised her hand and said she didn’t think this was a very good question. *“The purpose of the High Holidays is to look into your heart and become a better person. If you do this, whether you’re Conservative or Reform, that’s what God wants.”* Esther often has some wisdom to contribute to Torah study.

As Esther says, it wasn’t always easy to be a family with special needs at the Temple. Esther was a pioneer. She was the first person with special needs to be treated like any other 13-year-old when it came to her Bat Mitzvah. I remember a difficult conversation in which I was told that Esther would have her Bat Mitzvah on a Thursday morning rather than as part of the Saturday morning service. When

I asked why, I was told that this is how it was done: to spare Esther embarrassment and for the sake of the congregation. I remember taking a deep breath and saying: *“Esther will not be embarrassed. She will be proud of herself. She will read from the Torah and talk about what it means to her. She will make everyone cry, I promise you. And the Congregation will be delighted and gain something. Perhaps the temple needs to get over its own embarrassment and take a leap of faith.”*

We’ve come a long, long way in the Jewish community since then! The decision to schedule Esther for a normal Shabbat Bat Mitzvah had to be made at the highest levels of Temple leadership, and fortunately, it was made to the everlasting benefit of Esther, of all those with special needs who followed her, and of the Temple community as a whole.

We tend to think of inclusion as a way of giving the so-called disabled access to the world of the so-called normal. This is certainly part of it; but inclusion is as much or more about giving the so-called normal access to the world of the so-called disabled. An access which helps us all learn more about what it is to be human.

I remember, when Esther was 12 years old, we sent her to Camp Ramah. This was another pioneering experience in which she was the first physically disabled person at the camp. It was Esther’s first experience with overnight camp. While there, she severely dislocated her knee. But she refused to leave, finished out the season, and then came home in severe pain, and in a wheelchair. We were thankful she hadn’t broken her leg, which would have made the ninth broken bone in ten years.

“I had a great time at camp,” Esther smilingly told me. *“I was happy to be there, and I’m happy to be home.”*

I said: *“Esther you must know the secret of life.”* And without missing a beat, Esther replied: *“The secret of life is love people.”*

Those we call disabled are teachers. Every day they must bend to a world that is not made for them. To be inclusive, we must bend towards them. This involves extending the boundaries of our comfort zones. The so-called disabled wear their imperfections on their sleeves, whereas most of us do anything we can to hide our imperfections from the world. The so-called disabled remind us that we too are imperfect, that we too are vulnerable. We can learn from them how to be less afraid to expose our imperfections and our vulnerabilities. And to do the best we can with what we’ve got.

This takes courage. Esther is my ongoing education course in courage. Her courage is steadfast and daily, a necessary part of living every day of her life. Through her, I have learned that there is a sacred power in our vulnerability, in saying “I need help” and knowing how to receive it. There is a sacred power in extending ourselves to those in need—not out of pity, but because we are human and we need each other. Not just those of us who are “disabled” but all of us. We are all dependent on one another. In the human family and the family of the earth, we are all interdependent. When we create a more inclusive community, we do so not only for the sake of the most needy, but for the sake of all of us. For the sake of our souls. When we include the most vulnerable, we create a community that serves us all better. We make ourselves stronger.

Together, we make the miracle. We build the scaffolding of human interconnect-
edness that saves us from the abyss. We lift each other up and bring each other to
safe ground.

Thank you.