

A Grandmother's Wish

What I learned about love from Zev.

BY MARTHA LOEFFLER

It happened 65 years ago, but I remember every detail. The streetcar I rode to work was always filled with the same group of people, and friendly greetings filled the air. But like everyone else, I did not speak to the young man with Down syndrome who regularly sat in the front row. I have often thought about him. I could have smiled, or said hello, or sat next to him a time or two. I wish I had, but I didn't.

Now I am the grandmother of a young man who has autism. When Zev is out in public, people don't speak to him—they look the other way and pretend not to see him. They feel uncomfortable because he doesn't communicate in the usual manner, so they don't communicate with him at all. It would take so little and mean so much if someone would nod to him, or smile, or say hello. I have this feeling of déjà vu, and it makes me very sad.

Thanks to good, persistent teaching, Zev's language skills have improved, and with careful use of newer medications he handles changes more calmly. Zev also responds to affection, a new and prized achievement. It has not been an easy journey for his parents, but their determination and devotion have shown gratifying results.

What has *not* changed significantly over the years is the response of outsiders when they come in contact with Zev. Although the movie *Rain Man* brought autism to public awareness, it was not successful in changing attitudes. Zev is often ignored, glared at, and ostracized. He had no friends growing up. Once, on a trip with his father, he was even denied lodging in a motel. When Zev once jumped from the car at a busy intersection, his father raced to grab him and get him back inside, prompting a bystander to call the police. A charge of child abuse was narrowly averted.

Zev's parents have given up apologizing for their son. They take him where he is welcomed—to the gas station where the friendly attendant carefully counts the

change into Zev's hand when he buys gum, and to the drugstore where the pharmacist understands his need to smell the perfume bottles and align boxes on the shelves. As part of his public school program, he worked part-time folding boxes for a fast-food company, a job he enjoyed and performed well. Zev also swims, rides his bicycle, and likes to have his father read to him.

Recently, at age 25, Zev "graduated" from the public school system, receiving a certificate indicating his satisfactory attendance and the completion of his enrollment. He lives in his own house with around-the-clock caregivers; his parents live nearby and visit almost daily. But, at his age, Zev is no longer eligible to participate in the school-supervised work program that had formed the structure of his days. He is one of a burgeoning group of those with autism who are entering adulthood. Many are not able to live independently, are not employable in the traditional sense, and are unable to socialize acceptably, eliminating group home possibilities. With caregiver and financial help, many of them are able to remain outside of institutional care, which is



the ultimate goal. But the financial burden is generally more than the average family can bear, and the need for adequate governmental aid is rapidly becoming an urgent social responsibility. The ongoing concern for Zev's parents, like that of all parents of autistic sons and daughters, revolves around the question of what will happen in the future when they are no longer able to assist in their children's care.

We who know Zev accept him as he is. When I telephone and tell him that I am coming to visit, he says, "Grandma! Gooood! Bring gum," and my heart swells with love.

NN

Martha Loeffler graduated from the U.C. Berkeley School of Social Work in 1941 and began her second career as a writer in 1984.