



My hope



# Journey IN THE WORLD OF Special Needs

BY DOREEN WINTER, MSW

have had the privilege of knowing the special-needs population since I was young. I had a sister who was in this world for only a short time, but she had a big impact on my life. She had Down syndrome and died in her sleep of a heart disorder before I was born. I was told about my sister when I was nine, and when I was a young teenager, I started volunteering with the special-needs population in order to get an idea of what the sister I never knew was like.

Although I worked in a group home for people with special needs in New York in order to help pay for college, it was not until recently that I returned to work with the special-needs community.

I have held many jobs, with many different communities, since I moved to Eretz Yisrael over 18 years ago. When I interviewed to get my present job in Jerusalem as a social worker, I spoke of my love of this particular group and how my family had had a special-needs child. My current employment feels as if I've come full circle.

In my youth it was me looking for something, and now in middle age it is me looking to give back. In any event, I now feel like I am getting more than I am giving.

### Meet the Families, Hear Their Thoughts

I have been very touched and inspired by the families I work with. Parents have shared with me their journey with their special-needs child. They've described how they ran around to specialists — some even went to specialists abroad, trying new, experimental drugs or surgery to help their child. Constant hope, prayer and, of course, pain and stress accompanied them. I heard in story after story that one day, they understood: Hashem made this child! Hashem loves this child just as he (or she) is! After trying all they could to make the child into someone they thought he should be, they came to the conclusion that they just have to love him as he is. He is perfect, just as Hashem made him.

I once met with the aunt of a special-needs child. She said something that struck me as very wise: "My sister worries whether her daughter will ever walk. I worry if my daughter will walk into the street and get hit by a car." Every parent has worries, expectations, hopes and dreams for his or her child.



One of the people Mrs. Winter helps, lighting a menorah.

What we need to do is enjoy the gift we were given by Hashem — to learn to love and accept our children no matter what.

How do you love when you did not expect what you received? How do you learn to accept a child whom you never in your wildest dreams thought you would be given? How does a family cope with a situation where one of its members just cannot make it in this world without being carried and helped by so many others with the daily tasks of living? The commitment parents must make to care for their special-needs child is enormous. The fact is, their job never ends. This child needs their physical and emotional support, constantly, for the rest of their lives.

One mother shared her story of how she knew early on that she was going to have a Down syndrome baby. "The doctors in Israel ... tried reasoning with me about the expense of this child to the country. They warned me about how much it would cost me in time spent in hospitals, dealing with operations, therapies, special schools, and they told me that she will never be independent, she will always need me. I told them that I knew all of this. I told them I wanted this baby and I will love her just as she is. Today my daughter is six years old. She has had open heart surgery and will need surgery again. When she gets sick she really gets sick. I have to take days off from work. I know she is a gift from Hashem. I don't know how long she will be in our lives, but we truly love her."

The parents of special-needs children whom I have met have found a way to love their child even though that child may never smile or say thank you. It is a different love from the kind we are trained to expect, but they have mastered the skill to love fully, without expectation of reciprocation.

I went to an 18th birthday party for one of the boys in the home where I work. He is very low-functioning and has seizures quite often. He is not capable of much communication: he cannot talk, read or write. His mother shared with me details of his bar mitzvah. "David is our only child. We wanted to make a beautiful bar mitzvah in a hall with a band. We know he will never have a wedding so this would be the big celebration of his life. Friends and family came from all over. David seemed to be uncomfortable with the size of the crowd, or maybe something else triggered it, but he had a big seizure and had to be taken to the hospital by ambulance from the hall."

At this boy's 18th birthday party, his mother bought pizza for all of David's classmates. He sat impassively, without any sign of understanding. Then his mother went over, kissed David on the head and said, "I love you so much." She told me, "I saw a smile on David's face. It was like the sun shining." They were both truly happy.

### Eretz Yisrael and Special Needs

When I moved to Israel over 18 years ago, my husband, also a New Yorker, and I realized that we will never speak Hebrew like native Israelis, even though we are immersed in Israeli life. We still live in a bubble of the culture in which

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we were raised: the books we read and the car we drove at age 16. We came from a very different world from the one in which we raise our children here in Israel.

I am a fourth-generation American, so I didn't have to contend with immigrant parents. My children have immigrant parents, which results in inevitable embarrassing moments.

Parents of special-needs children must cope with a situation entirely different from that of parents with "regular-needs" children. In addition to that stigma, some of the parents I work with are also immigrants. This means they need to learn how to deal with the bureaucracy of their new, adopted country. They need to learn how to communicate their needs and feelings to the staff who work with their children in a language other than their native tongue.

Added to that, the family may feel alone and isolated. Very often they do not have extended family nearby to give them the respite so necessary for refueling with positive energy so they can meet their

daily challenges and not feel so overwhelmed and isolated.

Where I work we have started a special group for English-speaking mothers just for this purpose. Mothers can express their hopes, dreams, triumphs and failures. They can meet and connect with other mothers and communicate in their mother tongue with others having similar cultural backgrounds.

One mother shared with me, "When I came here to Israel 30 years ago, we came on our own. I did not know anyone. We had 13 children and Chana was our 14h. She has Down syndrome. I had no one to talk to, to share my fears and worries with. My extended family was not religious, so I felt like I had to protect them from our challenge and make everything sound nice and easy.

"Now here I am in a group with friends whom I can share with and give advice to. I can be there for others and others are there for me. I even get to laugh about the crazy experiences I survived. Someone understands me, and all that I have gone through."

The truly amazing thing that I find about these families is that even though they have, so to speak, two strikes against them (having a special-needs child and



facing the challenges experienced by new immigrants), many of them have mastered the art of looking as if they have it all together. They are living and building a home in Israel. They did not run back to their country of origin. They are staunchly loyal to their special-needs child and also to their choice of living in Eretz Yisrael.

*Life's Difficulties Make You Stronger*

Everyone seems to have a breaking point. To be the mother of many children, to live in a new country and to have a special-needs child seems like you would have to "lose it" at some point. Mothers have shared with me that at times they did feel things had become too much: the hospital visits; no family help and support (for they were alone in their move here); feelings of inadequacy to deal with such a demanding life.

Each mother could remember a moment when she had broken down and cried out to Hashem. All the women told me that they felt that Hashem carried them after that — that they were not alone anymore. They had a Partner and He would not let them down. And each father, separately, had someone to show him that he, too, had a Partner in raising his special-needs child.

One mother shared with the group: "I feel there is too much pain in carrying around my life like it is a secret. [Before coming to the group] I felt all on my own. It was like [carrying] rocks in your knapsack. The [disappointment] of a friend who could not be there for me is one rock I carry in my knapsack. The [disappointment] of having a family member (my sister-in-law) tell me to please get a babysitter for Moshie and come without him to the wedding. I know she does not feel comfortable with my



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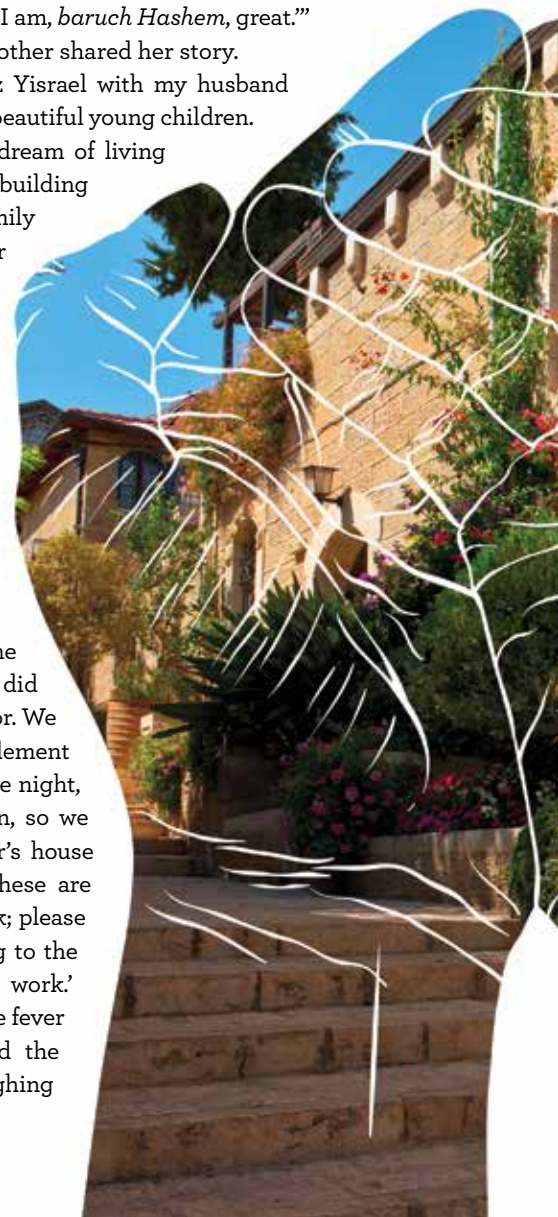
son, and does not want others to see him at her son's wedding. For me, this was another rock — a painful rejection I had to carry. I felt like the world just wanted to shut me out. How can I have guests for Shabbat? What will they think of my home and my family?

"I felt like the world wants me to stay strong and be perfect. People ask me, 'How are you?' They just want me to say, 'Great, *baruch Hashem*.' I did not want to be a person of secrets, but if you do not have people who want to know how you are really doing, that is what you become.

"Then I started going to a group with other women like me and I found a different world out there that wants to hear me and is proud of all of my triumphs. It took years but [now] I feel like I am worth something. Not alone and carrying this heaviness by myself. Other mothers have the same issues. We all just want to be good. We want to build a Jewish family and live in Israel. I am letting go of my rocks and I have real friends now, people whom I can talk to without shame. So when someone asks me, 'How are you?' I say, 'I am, *baruch Hashem*, great.'"

Another young mother shared her story. "I moved to Eretz Yisrael with my husband and my five perfect, beautiful young children. We were living the dream of living in Eretz Yisrael and building a beautiful family in the land of our forefathers. One of our first nights here, our baby had a high fever. We had just arrived, had no car, no friends or family. Just us as a team.

"We tried to bring down the fever on our own. During the day the fever went away. We did not go to visit a doctor. We were on a small settlement with few buses. In the night, the fever came again, so we walked to the doctor's house nearby. She said, 'These are not my hours of work; please come in the morning to the clinic when I am at work.' The next morning the fever was gone again and the baby was fine, laughing



and playing. That night the fever came again, and again we walked to the doctor's house and again she would not examine our baby. So, we called an ambulance to take us to the hospital an hour away. *Baruch Hashem* we did, because she had lost hearing in one ear and the second ear was about to close up. She had meningitis.

"People whom I did not know from this small community volunteered to care for my four other children while my husband and I were in the hospital with our baby for five weeks. Our beautiful daughter returned home to us alive. But she had issues. However, my daughter was alive and I had work to do — operations, therapy, special schools, but we were happy she was alive.

"Personally, we had a lot of work to do on ourselves. Why did the doctor not agree to look at our daughter? I asked myself, 'If the doctor had agreed to see our baby could she have been saved from all the pain, operations and worries?' When and how do you move on and just let go and be happy with what you have? All this

pain can break a person. I made a personal decision to be happy. I would love my child no matter what. Many have helped me along the way.

*"Baruch Hashem* my daughter is 18 years old today. She is loved and wonderful and has special needs. I am not alone because I chose to let Hashem help me, and He did not let me down."

### Volunteer or Visit?

I believe that to help my own children understand the world of special needs, it is important for them to visit the place where I spend so many hours of each day. I feel that it is important for their development as caring human beings to see where their mother works and to be exposed to the special-needs population.

Each one of my children has reacted differently when entering the world of special needs. I feel that these visits are like drops of water that can make an impression on a rock. The more often one sees special-needs people, the more comfortable he can be with them.

My son, who had volunteered for many years at Shalva, another organization in



Doreen's son, Asher, with a special-needs neighbor, Hillel Fasie.

Jerusalem for special-needs children, loved my workplace. Yet even he was a bit afraid at first, because he came to see them while he was in his army uniform. He found them all wearing ordinary suits or silk robes, black hats and white shirts with black pants. Slowly they approached him and gave him a warm welcome. Some held his hand, not wanting to let go. He spoke with them, and those who could, answered, and some just smiled. He seemed to feel their souls and their longing to connect. After observing the classes, work areas and the *kollel* he said, "This is a great place."

Another son who did not have as much exposure to special-needs people also toured the school. When we came to the *kollel*, the Rabbi introduced him to all the students. My son was dressed casually, while the students were dressed in their *chareidi* or Chassidische garb. After they welcomed him and shook his hand he said, "This is a true place of *ahavas Yisrael*. I love this place."

My youngest was afraid and shy. I pray that with time and exposure he will grow to love and understand that we are all souls looking for respect and love, and longing to connect to each other.

I must say, in the 37 years that I have been working with special-needs communities the world has become a kinder place for these children and their families. If only my parents had had the option of enjoying a warm and caring place 56 years ago when my sister was born they could have been spared feeling so alone and lost.

May we all continue to help *Am Yisrael* grow and see the beauty in the special-needs world, and appreciate its heroes, like those whom I have met, the parents of special-needs children. ■