



'For some of our [Shalva] children, the disabled marathon is the highlight of the entire year.' (Photos: Omer Benovici)

Changing times

Jerusalem's disabled marathon as metaphor

• By ARIEL DOMINIQUE HENDELMAN

The Jerusalem Marathon is still in its early stage. Begun just seven years ago, it has grown significantly in size. This year saw more than 30,000 runners participating, with approximately 6,000 of them running for charitable causes. While the various tracks of the main marathon start from Sacher Park, just past the park, the disabled marathon hosts thousands of participants as well.

The disabled marathon has become an incredible forum for children with disabilities to push themselves to try their best to tackle the 800-meter route, as well as for the organizations who are so dedicated to their care – to unite staff, volunteers, family members and even police officers in the cause of supporting the participants.

"We initially approached the municipality about doing a disabled marathon," Gaby Hirsch, international director of development for Shalva, says.

"We thought, if the marathon is to be an inclusive event, it should include the entirety of the Jerusalem population. Mayor Nir Barkat was all for it. Now it has become a much broader track with charities, soldiers and families all taking part. Shalva is the largest team."

Shalva, the association for the care and inclusion of persons with disabilities, had 500 high schoolers join from overseas who raised money through various initiatives, and nearly a thousand participants on their team in total. Team Shalva runners raised over a million dollars to benefit Shalva's children; an incredible accomplishment that will serve to help hundreds of disabled children.

"We had an injured war veteran who participated with us, so that was an enormous boost for the team," Hirsch enthuses. "It's really an amazing thing. For some of our children, it is the highlight of the entire year. One of our kids, Ma'or, can barely walk. He is deaf and severely physically disabled. He refused help. It was unbelievably challenging for him to get around the 800 meters, but he finished. He lives for the marathon."

For ALEH, the country's foremost network of care for children with severe complex disabilities, its team had fewer disabled participants because so many of them cannot leave the residential facility. Simply getting those who did participate to the marathon and into their walkers was a feat in itself. ALEH relies not only on the dedication of its own staff and volunteers, but on the police officers who visit the center weekly to help the children train throughout the year and are there supporting them, both physically and emotionally, on marathon day.

"Being a part of Jerusalem, we wanted our kids to feel a part of the marathon," Racheli Teller, community coordinator of ALEH, explains.

"Our kids are in wheelchairs and need help with everything in day-to-day life. They don't walk, so everything comes with a lot of effort. We put them into walkers and some would do three steps a day. A lot of training is required toward the 800-meter race. For them, that is a full marathon. We had more than 20 kids this year in all



Team Shalva, seen here at the marathon, was comprised of nearly 1,000 runners.

different kinds of walkers and some with special equipment. There were no limits to the effort involved to enable these kids to fulfill their dreams. Their families were there cheering them on and were amazed. These kids have it hard, but for one day, everyone is cheering and believing in them in such a clear way."

Jerusalem's disabled marathon is a beacon of inclusivity and perseverance, but not every disabled person felt it was for them. Maurice Eidelsberg, a 59-year-old Jerusalem resident with cerebral palsy, came to the marathon this year for the first time hoping it would inspire him to train for next year. He found himself disappointed in the overall lack of organization and that there was no option for an actual timed race for those who want one.

"I was curious, and was really excited and anticipating checking it out," Eidelsberg recalls, "but when I got there, it was like a big *balagan* [muddle]. There were so many



volunteers. I was thinking that there must be something else, so I kept asking where the handicapped race was, but everyone told me, 'This is it.' When it started, you really couldn't tell because it was a free-for-all."

Teller also alludes to the chaotic nature of the day, but not as a negative.

"At the regular marathon, there is more organization of course, but I think that the way the disabled marathon is run is working for us. Changes might make the slower kids feel bad. Just within the ALEH group, we have so many different levels due to different kinds of disabilities."

Eidelsberg is not the disabled marathon's target demographic, and he admits as much. He is a middle-aged man who does not have connections to any of the organizations whose teams comprise the near entirety of the event itself. Still, he is a member of Jerusalem's disabled community with a strong desire to participate, and would be unable to join any of the other races offered. In

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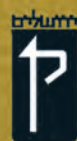
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‘Being a part of Jerusalem, we wanted our kids to feel a part of the disabled marathon’: ALEH children at the event, with Mayor Nir Barkat (center right). (Amos Buchnik)



Maurice Eidelsberg in his Rehavia home: Would really want to join a race. (Kumara Rajapaksha)

this way, he is caught in the middle; not belonging to the disabled or the able-bodied marathon.

“I guess I wanted to see that some participants really race,” Eidelsberg says.

“There were kids in walkers, which is how I hope to do it next year, and it was really nice to see the volunteers encouraging them. It was just disappointing for me. I didn’t feel like it honored those of us who would really want to join a race. On the other hand, I shouldn’t write it off just because it didn’t suit me. That doesn’t mean it didn’t serve any purpose. It definitely gave something to the kids who participated, and you could see that.”

Eidelsberg realized that for him, the marathon is a kind of metaphor for his experiences in Israel as a disabled person. The epitome of the attitude he has frequently encountered is encapsulated in a phrase often directed at him while going around his neighborhood of Rehavia: *refua shlema* (wishing him complete recovery).

“When I hear that, I know that some people look at me as sick,” he says. “People look at me and think that I’m suffering, that I have no job or even that I’m mentally challenged when I’m not.”

He tells a story of seeing volunteers collecting money for summer camps for disabled children in the Mahaneh Yehuda shuk.

“One time, there was a guy with a megaphone saying, ‘Help the kids who suffer from CP!’ I asked him if he could change it to, ‘Help the kids who have CP.’ Why do you have to say ‘suffer?’ That’s another assumption that people make. It hasn’t reached people’s consciousness yet in Jerusalem that disabled people can be part of mainstream society. I have met plenty of people here who treat me wonderfully, so I know I’m generalizing. But the general sense in this city is that disabled people need to be taken care of and that’s it; that they don’t have any other needs.”

It is crucial to make a distinction that, as with everything in life, there are many varying levels and types of disabilities. To speak in sweeping terms of “disabled people” as a uniform category is inherently flawed. What’s helpful for some may not be for others. Thus it would be nearly impossible for the disabled marathon to cater to every disabled person. As a well-functioning

man who lives on his own with the help of a full-time aid, Eidelsberg often finds himself caught in between the disabled and able-bodied worlds.

While living in Ramot in 2002, the same year Eidelsberg began to require a wheelchair, accessible buses with ramps were being introduced by Egged. Initially, Eidelsberg had to travel 15 minutes to the other side of Ramot for an accessible bus.

“Then you never knew when one was going to come because not every bus was accessible,” he recalls. “When one did come by, sometimes it wouldn’t stop. That made me go crazy. I would go ahead of the bus, in front of it, and not move. Then they would motion me to come get on, and then drive away.”

These encounters came to a head one day on Jaffa Road (before the light rail). Eidelsberg went in front of a bus that wouldn’t stop for him and ended up backing up traffic down the entire street. Channel 10 came to film him and the bus driver still would not open up the door. It took the arrival of the police for the driver to finally allow him onto the bus.

In the wake of the incident, nothing changed, but Eidelsberg finally saw real improvement with the accessible bus problem once a legal organization called Bizchut became involved.

“They organized it so that I could go around and help sensitize the Egged drivers,” he adds. “I must have talked to 150 drivers before the program was discontinued.”

Shortly thereafter, Eidelsberg moved to Rehavia and could get to most places without a bus. On the rare occasion when he does take the bus now, he concedes that the situation is markedly better. Bus drivers stop for him, pull all the way over to the curb, and even walk to the back to help him. Change takes time, especially when that change involves an entire city and notoriously stubborn bus drivers, but slowly, it has happened.

“The pervasive philosophy that I’ve encountered is *hessed* [loving-kindness], so people are always helping us in a loving way,” Eidelsberg states. “That’s the good side, but the downside of it is that it sometimes comes without respect. In Jerusalem especially, it’s also connected to religion. People are always telling me that when *Moshiach* comes, I’ll be walking without a wheel-

chair. I say that I love my wheelchair. They can’t think that maybe I’m okay.”

Eidelsberg was raised modern Orthodox and has mostly negative memories of his experiences with synagogues and yeshivot in New York. He remembers feeling unwelcome. But five years ago, he found a Chabad synagogue called Beit Menachem.

“They not only accept me; I feel like I’m a member of the community,” Eidelsberg shares. “They give me aliyas and even let me lead *shaharit* [the morning prayer service]. They wanted me to and were excited about it! When I had my daughter, they called me up so that I could give her name and danced around me!”

For Eidelsberg, feeling like a member of his Chabad community has given him a place where he can go every day and simply be. He still wants to participate in the marathon next year, and has been training every day with his caretaker. He is now able to walk with a walker for more than 50 meters. Like accessibility in Jerusalem itself, the improvement is slow going, and from day to day, he doesn’t often see significant change, but subtle as it may be, with work and dedication it is happening.

In terms of the future of the marathon, Hirsch emphasizes that the logistics are not simple.

“Somehow we manage it and we work closely with the municipality, whose workers are fantastic in helping and supporting us, but people underestimate the importance of signage. When you get in there and it’s marathon day, clear signage would be a huge help.

“Despite logistical difficulties, I think if you moved it to Teddy Stadium, there would be something missing. The whole beauty of this is that it’s part of the marathon. If you moved it somewhere else, it’s like saying that these people are all different and should be separated. Then it’s not inclusive. You can see the power of inclusion in the disabled marathon. The children don’t just sit on the sides; they take an active part.

“These children are, in a way, facing marathons every day of their lives.”

For more information:
jerusalem-marathon.com/Jerusalem.aspx
www.shalva.org/
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