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Oct. 23, 2002

Handicapped hearts, By FRIMET ROTH

Netanya Mayor Miriam Feiberberg is in it up to her neck. For the past two years, she has stubbornly refused to sign a permit for the construction of a hostel for mildly retarded young adults, all Netanya residents, in the neighborhood of Neot Ganim. The much-needed hostel, to be operated by the Akim organization, has satisfied all the municipal planning requirements. Surrounding owners of single-family homes have failed in their three legal appeals against the project. Last month an exasperated Akim filed a personal lawsuit against the mayor for failure to execute the court decisions.

But the Neot Ganim folks are a headstrong lot when it comes to worthy causes such as this. On October 13, their zeal to exclude the retarded propelled them to the High Court of Justice in an action against the Interior Ministry, the municipality of Netanya, the local planning committee, and Akim. Their representative has vowed to continue their fight, if all else fails, "outside the walls of the courthouse." These are the voters with whom Feiberberg has chosen to cast her lot. I wish I could have brought the misguided mayor with me to the funeral last week of a very special 10-year-old boy.

For most of his life, Ro'i had been imprisoned within the cruel confines of Canavan's disease, a genetic illness exclusive to Ashkenazi Jews which left him blind, neurologically impaired and drip-fed via a jejunostomy a hole in the lower abdomen.

At his small grave stood his devastated mother: young, slim, her blonde corn-rows fastened with multi-colored rubber bands. The outward trendiness of her appearance belied a steely courage within. Throughout his deterioration, she had nursed and loved him, her only child, with an

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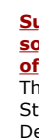
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awesome devotion.

She always insisted on the best but least-invasive care possible for him.

At times, the doctors were reluctant to invest efforts in a patient who was certain to die in childhood. At others, they were eager to employ painful procedures with doubtful benefits after all, Ro'i was retarded and non-verbal. But she is a spunky, tenacious aerobics instructor and she usually got her way. Ro'i lived at home, attended Keren Or a school for the blind and multiply handicapped and enjoyed outings to the mall. His neurologist told me he survived years longer than any doctor expected, thanks to his mother's dedication.

Also present at the funeral was Ro'i's father. I knew who he was only because his shirt collar was ripped like a mourner's. But he stood alone at the rear of the crowd, crying a little. At the end of the service, he did not say Kaddish.

A young man who had beautifully eulogized Ro'i earlier was the one who recited it. The father did not object. He had forfeited the right to say a father's Kaddish 10 years earlier when, after some misdiagnoses, doctors informed the young couple their son had Canavan's. Roi's father promptly abandoned his child and divorced his wife. Other than occasional visits at school, the father contributed nothing toward Ro'i's care. He thus spared himself the pain of watching his son's slow death.

He never endured those sleepless nights when Ro'i's lungs gave out and he needed to be connected to the oxygen tank in his bedroom. He escaped the innumerable emergency trips with Ro'i to the hospital. And he ducked the five-figure debts accrued from rare medications. His mother contended with all those alone.

BUT THE father also cheated himself. He missed out on seeing Ro'i's huge smile whenever he listened to his favorite songs and stories. He denied himself the love Ro'i gave everyone who loved and doted on him.

My late daughter, Malki, murdered in a terror bombing last year, was one of those who helped care for him from time to time. Malki had an incredible knack for disregarding handicaps with which Ro'i was amply encumbered and enthusing over a child's limited reactions. In Ro'i's case, his appreciative smile was the only reward she needed.

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Just as Ro'i's parents responded in divergent ways to their son's disabilities, so too can entire communities react differently to the presence of the disabled in their midst.

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The Neot Ganim residents who have threatened that "hot-headedness will result and who knows what that can lead to...?" represent one kind of welcome for disabled neighbors. They say the mildly retarded neighbors will disrupt the "calm and beautiful" environment they and their children currently enjoy.

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They also anticipate "a significant drop in their real-estate values." They have generously suggested the "many alternative sites in the industrial zone" of the city. According to press reports, their spokeswoman says she has nothing against the disabled and is even willing to help raise donations for Akim to build on an alternate site.

The response of Neot Ganim is not at all rare. Many Israeli organizations have encountered opposition to the presence of the disabled in their midst. Today, mayors, in contrast to Feierberg, usually strive to allay neighbors' concerns and ease the integration process. But there are instances where institutions have been relegated to industrial zones which, contrary to Neot Ganim residents' beliefs, are highly unsuitable.

Aleh, a Jerusalem institution for 70 severely disabled children, stands on such a site. It is surrounded by car-repair garages, tire suppliers and dirt paths. Pleasure walks are out of the question wheelchairs get stuck in mud. Aleh's pent-up children see nothing but dismal, gray structures through their windows.

Not every neighborhood is as narrow-minded. In my own, the Jerusalem suburb of Ramot, stands Keren Or, the school that Ro'i attended. It moved into its present home, a bright, modern building, 10 years ago. Since then it has expanded to several nearby apartments where its young adults live.

The sight of blind and mentally retarded youths chatting and laughing with their counselors during their daily walks is now common in Ramot.

It has shown us unpatronizing acceptance of people with disabilities.

Many have even been inspired to work at the school either as volunteers or employees. I was moved to enroll my own disabled child there last year.

The presence of those mildly retarded would undoubtedly have the same positive impact on the primitives of Neot Ganim. Submitting to their demands and hooligan-like threats for political pay-off may suit Mayor Feierberg. But it will stave off progress that other developed countries long ago made. Dumping the disabled in our industrial zones out of sight and mind will entrench the quagmire of this suffering minority.

Worse yet, our healthy children will be denied the chance to have disabled neighbors, to develop new attitudes, and to learn the powerful lessons that they, like Ro'i, can teach us.

Ro'i's surrogate father, the young man who recited Kaddish, said this in his eulogy: "We were always students/ Learning from you/ How to get up in the morning and smile against all the odds/ To rise above all the physical handicaps toward the spiritual."

For those of you who did not merit to meet these heroes Ro'i, his mother, his surrogate father and, in particular, for Mayor Feierberg and her Neot Ganim residents, this is their story.

The writer is a freelancer living in Jerusalem. The memory of her daughter Malka Chana, who was murdered in the Sbarro massacre last year, is honored via Keren Malki, a not-for-profit organization which helps to provide for the needs of families of children with severe disabilities.
www.kerenmalki.org.

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