

# Group Homes - Making the Decisions

Gila Arnold

It's something every parent prepares him or herself for. From the moment their child is born, the clock starts ticking as time marches towards that inexorable day of separation. For most typically developing children, that separation, which begins when the child is weaned, toilet-trained, and heads out to his first day of preschool, culminates in marriage and leaving to start his own independent life.

For children with special needs, the road to independence looks quite different; in most cases, total independence is never achieved, and in some, the child remains completely dependent on caregivers even as his age registers "adulthood." However, this does not mean that separation does not take place. For a young adult with special needs, leaving his home to move into a group residence represents a leap to a new stage of life on par, perhaps, with marriage. (One mother, in fact, to mark this momentous occasion, threw her daughter a "wedding", complete with gown and dancing.) And for the parents, the separation carries with it the same mixed bag of emotions that all parents go through – with some others thrown in that are unique to parenting a child with special needs.

## *When is it Time?*

Raising a child with special needs takes a huge amount of energy, patience and love, and is a job that takes over a parent's life. What factors make parents decide that the time has come to move their child into a group home?

For some, it's the realization that the intensive physical care their child requires has be-

come too much for the parents to handle.

Miriam's 20-year-old daughter has severe malfunction of the central nervous system, and cannot walk, talk or eat on her own. She recently moved into a New York-based group residence. "Considering the amount of care she needs, it became increasingly difficult to have her at home," says Miriam. "As hard as it is to say this, a group home is designed to care for all their needs."

For Tzirel Friedman, mother of 20-year-old Shua, a young man with Downs Syndrome and a high level of need, who has been living for three years in a group apartment run by



the Jerusalem-based Seeach Sod, it was the realization that, though she was still able to care for Shua's physical needs, "There comes a point in a child's life that he needs the expertise of the professional staff in a group home to help him advance in his development and deal with his issues in a way I couldn't."

Others say that the decision for the move was based primarily on the social benefits for their children, living among peers.

"We needed to help him expand his horizons," says Ruth\* of her son, Binny\*, who moved into a Seeach Sod residence when he was in his low 30's. "While he was happy at home, we felt he was missing something in his life. He needed a chevrah, activities, a home where all his needs would be met. We knew that our job as parents was to give him what he needs."

Sarah Sanders, mother of 27-year-old Moishey who has Downs Syndrome, and publisher of the magazine Downs Syndrome Amongst Us, relates, "When Moishey was younger, I was always under the impression that because he is our

Of course, underlying the other factors is the age element, and the realization that even the most energetic and devoted parents will not be able to care for their child forever.

"It's the way of the world that a parent predeceases his child," says Dan Goldberg\*, whose 12-year-old son with severe autism lives at home. He says that while he intends to keep his son at home as long as he can ("Until I breathe my last breath"), he recognizes that "At the end of the day, my son will have to be in a group home, and I will have to give him time to properly transition to that reality."

And, indeed, knowing the right time to start that transition is an important part of the process. Since, as Dan points out, assuming the child outlives his parents, he will need to eventually be placed in a group home, those in the field say that it's best for parents to start this process early enough that they can be the ones making the important decisions and guiding their child through the process, rather than leave it to an emergency, default placement.

## *Separation Anxiety*

While studies discuss the phenomenon of separation anxiety in children, we all know that it is felt just as acutely – or even more so – in parents. How did these parents feel the day their children "flew the coop"?

"The morning Moishey left with his suitcase in tow, it was Tisha B'av for me," says Sarah, who admits that she felt conflicted about the decision. "I cried and cried and couldn't collect myself. My 13-year-old daughter was sobbing into a

tissue of her own, and it was a hard morning.” Nevertheless, she says that within a few days, she already saw beneficial changes in her home, and realized it was a good decision.

Miriam vividly describes the strong emotions that came to play in her decision and came to the fore when her daughter moved out. “My Hindy was born a normal and beautiful baby. She nursed well and was happy and cute. We were told not to worry about her slow or lack of development. Then, eventually, she was diagnosed with a central nervous system disorder. We had to fight to feed her solids and purees. We tried almost every therapy, every piece of equipment known to man to help her. We even figured out how to stop her seizures. And after all that work, we have to send her to a group home? Our first thought was, never! Well, reality caught up with us and we realized

that some of the care that she needs, we simply cannot provide.” She says that most of her family has still not gotten used to Hindy’s recent move.

Tzirel says that, even though they had placed her son on a waiting list for a spot in a group apartment, the spot opened up so much quicker than they’d anticipated that she wasn’t emotionally prepared. “The social worker called up and said, ‘Your son can move in tomorrow.’ And I said, ‘Tomorrow?’” She says that, though she understood that they were getting older and it would be harder as time went on to care for Shua herself, still she found it very difficult to deal emotionally with the thought of sending her son away.

“It’s like those Gush Katif slogans – *Yehudi lo megaresh Yehudi* (A Jew doesn’t chase out another Jew). Well, I felt, a mother doesn’t chase out her son. How could I?”

Ruth, however, said that her emotions were purely positive, and the primary one was gratitude. “Lots of gratitude to *Hakadosh Baruch Hu* that we found a place that our son could be cared for with respect and love. And gratitude, as well, that we met our goal. While we had been happy living in our community in the U.S., we realized that there was no appropriate place there for our son, and so we made Aliyah in order to send him to Seeach Sod. So yes, we were proud of ourselves, for fulfilling our parenting responsibilities towards our son, by moving to where he needed to be.”

### Group Living - Options and Benefits

While the decision can be arduous for the parents, for the young adults there are, in fact, many benefits to living in a group home setting. Just like their typically-developing peers, they, too, have a

desire to establish their independence and move into a home of their own – particularly when they see their younger siblings achieving this milestone. Living in a group residential apartment, these young men and women are now able to invite friends and family members over to their place, enabling them to feel the joy of being a “ba’al habayis.” In fact, many parents report that their children end up achieving higher level of independent functioning after leaving home.

However, even once the decision is made to place a child in a group home, it is not a simple thing to secure a spot.

“The placement issue is a really big one,” says Miriam, who lives in the New York area. “You are supposed to get yourself on a waiting list, and, I believe, someone decides how much of a priority your case is. We were on a waiting list for 5

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