Group Homes - Making the Decisions

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?

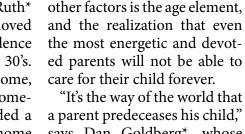
Raising a child with special needs takes a huge amount of energy, patience and love, and is a job that takes over a parent's life. What factors make parents decide that the time has come to move their child into a group home?

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



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."

Of course, underlying the

Gila Arnold

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



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.

second child and was followed by 4 more siblings, our home would continue to bustle with activity for many years and it would be the perfect setting for him. But it has proven to be just the opposite. The gap between his development and that of his younger siblings keeps widening and it creates behavior challenges. In addition, with his long days at the yeshiva, his time spent at home was very limited and fraught with difficulty and mood swings. It was time to make the move."

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



years – apparently, we weren't priority enough. Eight months ago, I demanded to know how the priority system works. I didn't really get an answer – but somehow, I got moved up the priority list."

Unfortunately, she says, no new homes are opening and the demand is great. In fact, those institutions that run group homes for the religious community do not even advertise; they have no need, because as soon as a slot opens up, it is immediately filled.

Sarah, who hesitated to place her son in a standard group home, helped develop a new option: Yeshiva Bonim Lamokom, the yeshiva for boys with special needs that she and her husband founded 15 years ago, recently opened a dormitory division, the first of its kind, for students to live in during the week. They are out at their day-hab program in the yeshiva from 9 AM to 7 PM, and come back to their supervised dorm to relax and socialize in the evenings. Students go home every Shabbos and Yom Tov and whenever else they want to be with their family. As she puts it, "We have no strings attached to any agency." She says that since going to live in the dorm, Moishey has become much more responsible, taking care of his things, and putting his laundry in the hamper at home.

Tzirel, like Ruth, says that she made Aliyah just in order to enroll her son in Seeach Sod, and is extremely enthusiastic about what they've done for him. As one example, "At age 17, when we first sent Shua, he was not toilet trained. As much as we'd tried, we were never able to make it work. Well, the staff at the home, in conjunction with the staff at the (Seeach Sod) school, decided they were going to take this goal on. They worked with incredible patience and perseverance. First, they taught my non-ver-18 December 2016

bal, cognitively-impaired son how to make a sign to express his need to use the bathroom – and eventually, after much effort, they managed to train him. For us, this was nothing short of an open miracle."

She says that, while there's no replacement for a mother, the level of professionalism and care is unsurpassed, and the staff is also very open to her involvement. As she lives right across the street, she is scribes as needing constant supervision, and who, at 12 years old and nearly 180 pounds, is too big for anyone but his father to handle when he succumbs to his frequent tantrums, insists that he will keep his son home as long as possible, because he can't imagine him getting the same care at a group home as he would from a loving parent.

"When you send your kid to a home, you lose your say in



able to see her son frequently.

And, she says, a fringe benefit of the arrangement is that, after so many years of caring for her son, she finally has time for herself.

"My members family thought this was a great decision from the beginning, that I would finally have a life. I myself hadn't recognized that need; when you're in the middle of something, you don't stop to think, 'what can I be doing for myself' because you're so busy with it. But my family members noticed, and thought it would be a healthy thing for me – and they were proven right."

No Replacement for a Darent

While these women are all thrilled with the care their children are receiving, and feel they made the right decision for the overall benefit of their families, there are others who choose a different route. Dan Goldberg, whose son he de-

how to deal with him. Even if they listen to your input, at the end of the day, you're not there. For all their good intentions, in a group setting the staff ultimately has to do what's best for the group as a whole. And if my son is having a tantrum, and you have a staff worker who's maybe not the most patient type, it's much easier to say, 'up his medication' and throw him a pill which will knock him out the rest of the afternoon than to sit with him and work to calm him down."

(It should be noted that, in New York at least, caregivers are not allowed to up the dosage of medications on their own. There is an approved dose range that the parents/ guardians must consent to, and a human rights committee that must approve any medication for behavioral reasons.)

While he acknowledges that his son's outbursts can be frightening because of his brute strength, Dan says that he has learned how to calm him down in just 45 seconds – by wrapping his arms around his son and exuding love.

"That's what every child really needs – to feel loved and cared for. My son, being nonverbal, just can't express it." Dan says this only works if he can bring himself to a state of mind where he is feeling only love and calmness, not anxiety or frustration.

"Would he get this in an institution?" he wonders. Would the staff be able to show him the love that a father can?

He acknowledges that, though ideally he would like to care for his son at home all his life, there are circumstances that would induce him to send his son to a group home – such as if his son was putting other family members in danger, or if he reached the point where he were physically unable to care for him. Yet he is also quick to point out that there is no right or wrong on this issue.

"Everyone has to do what's right for them and their family. I don't like when people say statements like, 'If Hashem gave you this challenge, then He gave you the strength to deal with it, implying that anyone that's sending their child to live outside the home has failed their challenge. Guilt is always a powerful emotion, but there's no failing involved here."

True words indeed. For, at the end of the day, whether parents choose to place their children in a home or care for them in their own home, there is no replacing a parents' love, and that is something that these parents excel at – by ensuring that their child lives up to his or her potential in the setting best tailored to his needs.

Gila Arnold works as a freelance writer and a speech therapist. She is a regular contributor to several Jewish publications. Gila lives with her husband and children in Ramat Beit Shemesh.