



Why I Placed my Disabled Child in a Group Home

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There's a neighbor in our building who will no longer acknowledge us. She used to be friendly, but now she won't say hello or even make eye contact. Once she let the elevator door close in my face after I asked her nicely to hold it. Her hostility started in the summer of 2008, right around the time we sent our then 10-year-old son, Jack, to a group home.

I'm sure she's not the only one who's outraged that we "put him away." But I don't care — he'll be 16-years-old soon and I have no regrets. In fact, there are not many things I'm certain of, but one thing I know for sure is that we did what was best for all of us, and that includes Jack. Because he can't talk or feed himself and is physically challenged, Jack needs assistance with every aspect of daily living. He is also unable or unwilling to drink, so he gets all his liquids through a feeding tube (figuring out the reason why, after the umpteenth ICU hospitalization for dehydration, stopped mattering).

When Jack lived at home, we depended on aides seven days a week and sometimes for overnight shifts. Some of the aides were nice to him, but not to me. Some were nice to me, but not so great with him. I was friendly with a few, others gave me the creeps. Dealing with them was difficult in all the ways that managing employees can be and more, but I was desperate to keep the rotation going. With two other kids and a job, I lived in fear that one day someone wouldn't show up.

Sometimes there were fights between the aides and me over scheduling. One weekend, I suspected that two day aides were trying to sabotage the night aide by leaving their shifts without having properly cared for Jack, in hopes that the night aide would be overwhelmed and quit over his agitated, deficient state. Our home had become a dysfunctional workplace, with all the ugly cutthroat competitiveness and politics that go along with it.



I once received an anonymous multi-page letter in the mail from a neighborhood parent who had observed my son with his aide in the park and felt his care was “not as good as it could be.” Yet this particular aide was extremely punctual and reliable, and it seemed too risky to give that up. In fact, the thought of trying to get through even one day without help scared the hell out of me. Sometimes I would feel bad that Jack was in his pajamas in bed at 6 o’clock when other boys his age were still active. But the aide had spent hours feeding and bathing him and was exhausted and ready to go home. And I was tired, too. I know of a family who can’t bring themselves to place their autistic 22-year-old son in a group home. He lives in a big house with his parents, attending a day program and languishing alone in the backyard, swinging on a swing or ripping up leaves. I heard his mother adds vodka to her morning orange juice and doesn’t stop drinking till bedtime.

Now, Jack lives in a brownstone on a quiet block with a group of other boys his age. There are several counselors there who work as a team to provide for his basic needs. They’re young and strong and never seem tired. When Jack lived with us, his aides used to wheel him around in a big stroller. Now, his counselors prefer to hold his hand and walk with him everywhere, improving his strength and balance every day. His home also has a nurse, social worker, den mother and manager. He is never alone, and neither are his caretakers. I never worry that his needs aren’t being met. In fact, I know his needs are being exceeded in ways they never could be when he lived with us. Whenever Jack is off from school, the team takes him and the other boys on a trip to an amusement park, concert or movie. Although we try to visit him every week, sometimes his schedule is too jam-packed to squeeze us in.

Twice a year we hire an aide and take him on a special family vacation so we can all be together and his brother and sister can bond with him. They were young when he lived at home and probably don’t remember much, but I know they’ll remember the good times we have with him now. Granted, not all group homes may be as great as the one we found. But because Jack will never be able to live alone or care for himself, and we know that one day my husband and I will be old—and, eventually, dead—putting him in one was simply inevitable.

It’s pretty much impossible to have complete peace of mind about your children’s futures but ironically I do have it with him. I’m so grateful he’ll be able to live where he is with his housemates for the rest of his life. And because we had this opportunity and made the decision early on, we all gained so much--Jack included.