

My brother Jay is a resident at Abilene State Supported Living Center. He is 25 years old and has lived there for 3 years, and it is absolutely the best place for him. On a very regular basis, Jay and other residents at the living center are given information about moving out into the community, and a very rosy picture is painted about how great life would be away from the state facility. Jay has already experienced life in group homes, and I want to tell you what that was like for him and for our family.

When my parents realized that they could no longer care for Jay at home, they were first steered to local group homes, where Jay was a resident for several years. Jay is now a six foot tall, 200 lb, mildly retarded man with paranoid schizophrenia, who doesn't know his own strength, and while can be sweet and funny, he is also prone to violence. He has been bigger than all of us for a long time. On his good days, caring for him is exhausting since he needs constant stimulation and activity; boredom always leads to trouble. On his bad days, Jay breaks out windows, throws televisions, punches people, and sometimes tries to kill himself.

At the first group home, there was a very high turnover of staff, because the workers were not equipped to handle Jay. He literally wore them out, and they quit, one after another, which was really difficult for him because of the lack of stability. Jay was frequently parked in front of the television because many of the staff members couldn't be bothered to engage him in activities or outings. And Jay has always wanted to be a cop, which I suppose is why he enjoyed standing in the street outside the group home, trying to flag down cars. He was pretending to be a policeman handing out tickets. We lived in fear of Jay running away, or being hit by a car, since it didn't seem like they kept a close eye on him, and didn't keep him very safe. We were also afraid that Jay would injure or kill someone and end up in arrested and imprisoned without ever understanding what had happened. We brought Jay home on Saturdays, and when we picked him up, he was usually out in the street waiting, sometimes with a staff member and sometimes alone.

When we had had our fill of group homes, the caseworkers at our local Betty Hardwick Center were opposed to allowing Jay into the Abilene SSLC. "It's like putting him in prison," we were told. Being familiar with the SSLC, we knew that was a ridiculous statement, so we pushed forward, but it was extremely difficult to get Jay placed there. It did not matter to them that we thought the Abilene SSLC was the best choice. They were familiar with Jay and his history, but they still insisted we try another group home. I find it baffling that the Sunset report gives "enrollment is down" as a reason for closing facilities, because apparently the caseworkers who should be offering the SSLC as an option for people like Jay are doing all that they can to prevent anyone from getting in. It's not a jail in any respect – it is a SAFE place – a safe campus with responsible staff members who watch my brother carefully. The speed limit is 15 mph, and it's enforced, not like in a neighborhood where a group home would be. And if he makes a run for the real road, where the cars drive fast, there's a fence. I'm grateful for that fence. I'm also grateful for all the other places on the campus Jay can safely walk to: the nature walking trails, activity center, chapel, gym, diner, shop, clinic, barber shop, movie theater. It's nothing like the jail it's

detractors are trying to make it out to be. It's a community, almost a small town, and it would be a travesty to take that away from the people in our society who truly need it.

I disagree with the argument for closing SSLCs because the cost per resident is so high. Some of the people in our society, like my brother, are simply expensive to care for. Putting those people in group homes will not make them less expensive. If Jay were to return to a group home, consider these expenses: High staff turnover (due to burnout from difficult clients) requires more recruiting and training and will eventually drive up the cost of the employees. Frequent calls to the police and crisis intervention staff is expensive. Replacing broken furniture and repairing damage to group home property can be expensive. Installing cameras when incidents with clients like my brother become widespread and need better monitoring will be expensive, as will the increased regulations and paperwork that is sure to follow. And I expect there will be lawsuits from communities and families until the group homes are just as regulated and expensive as the SSLCs, because clients like my brother, when you take them out of a safe environment like the Abilene SSLC and put them out in the greater community, hurt themselves and others. It's a disaster waiting to happen.

What about all the incidents of abuse already at the SSLCs? My brother has reported a few. Actually, he's reported a lot. Jay is smart enough to know that anyone he reports for abuse will be immediately reassigned, and he uses that to his advantage. If he gets irritated with a staff member for some imagined reason, he reports them for abuse. They're reassigned and he gets someone new and interesting right away. The investigator comes and asks him questions, video recordings are reviewed, and everything is thoroughly checked out until a conclusion is reached. Usually Jay gets around to confessing to my mother that he was just mad and nothing really happened. And while he's smart enough report false abuse cases in order to remove someone he doesn't like, he's not so smart when it comes to what he actually reports, such as "he cut off my private parts." Which takes only a minute to disprove.

Incidents of abuse were a bit different in the group homes. We rarely knew what was going on. Jay was at the mercy of one or two people in a home who frequently got tired of him or irritated with him and, I believe, treated him badly because no one was there watching. The other clients were not as vocal as Jay and could not speak up. Because no one ever knew whether Jay could be believed or not, much of what he said was discounted. If an incident of abuse happened on a Monday, and we didn't speak to him or pick him up for a visit until Saturday, he would likely not remember or be able to explain it to us. So we bought him a cell phone and started speaking to him daily, and then we got a lot more information. Jay was taken to the house of a staff member (prohibited) but was not allowed to sit on her furniture, something Jay didn't realize was inappropriate. Jay was taken to a strip club (prohibited, plus he was only a teen at the time) by one of the staff members. Another time, two female staff members repeatedly called a crisis worker to come evaluate Jay. This crisis worker happened to know my sister, and confidentially told her that those two workers had successfully had other clients in the home sent to the state hospital, and they were pushing to have Jay sent there as well, but there was no evidence that he needed that kind of treatment. Luckily she warned us and we were able to report them and prevent

that from happening. Those are a few incidents that come to mind, but over time it was obvious that the majority of the workers in the group homes were not professional and not equipped to handle Jay. And there was no oversight at the locations. At the Abilene SSLC, there are people everywhere. There are cameras. There are procedures. There are well-trained professionals. I cannot stress enough how professional the staff members are at the Abilene SSLC and what a great job they do with my brother.

We didn't stop with one group home. We tried another, at the insistence of the caseworkers at the Betty Hardwick Center, and this second group home refused to care for him after just one week. "Come get him, or we're calling the police." I find it appalling that those two group homes are really the best Abilene has to offer. The level of care they provided was a far cry from what is available at the Abilene SSLC. I've also had Jay live in my home. I thought if I could make Jay my full time job and devote most of my time to him, I could do it. I bought a house with enough space for him, and I had big plans about how to make it work, and lots of help lined up. I am young and strong and capable, and I love my brother, but I was unable to care for Jay. He shoved me down, he toppled furniture, he came close to hurting my kids. When I was driving and Jay grabbed the steering wheel, almost making me hit another car, I knew it was not going to work. It was not safe. There is not a safe place in the community, aside from the Abilene SSLC, for Jay to live. He is a danger to himself and others. But the Abilene SSLC is a wonderful chance for him and others like him to have a place of their own where they can have quite a bit of freedom to do normal things while still being safe.

Jay has a job on campus at the Abilene SSLC: he folds towels, and he gets paid. He can not read or write, but his job is something he can be proud of. He goes to church on Sundays. He goes to the diner to eat out. He can play sports or go on a nature walk or see a movie or go shopping or do any number of things on campus without having to worry about fitting in in a certain way. He has friends in his cottage, both among the staff and the other residents. And his family can visit him on the campus and do any of these things with him, and we frequently do, or we can take him home for a visit.

Obviously I don't want the Abilene SSLC to close, but I would like to add that for the people who truly need this level of care, like my brother, I would like to see the gates opened wider so it is less difficult to find placement there. I think the Abilene facility should be expanded to serve more people. Closing our facility is the opposite of what needs to happen.

(This note was written for Facebook and is included here to illustrate the problems with group homes for some clients, and the difficulty getting placement at the Abilene SSLC.)

4/29/11

Jay needs help.

Right now, we think he is at Acadia, but we don't know for sure and we can't talk to him. His Mom called to check on him, but they wouldn't even confirm he was there.

Mom: I'm his legal guardian.

Acadia lady: You could be anybody.

Mom: How can I contact him?

Acadia lady: IF he is here, which we can neither confirm nor deny, he has to call you and give you his patient number. He knows his rights.

Mom: You don't understand; he's retarded. He doesn't know how to use the phone, except for his own speed dial phone, which apparently he doesn't have.

Acadia lady: (my paraphrase) Too bad for you.

Later we got a report from some caseworker that he has asked to use the phone. It makes me really sad, because I know that means he wants to call Mom and doesn't know how.

We could get permission to contact him if his caseworker from Betty Hardwick could call and inform them, but of course she's not in the office today. And doesn't work weekends.

Why, you ask, is he at Acadia? I'll tell you: after a mere three days in his new group home with Draco, he acted exactly the way we told them he acts when he gets upset. He was angry, threatening, and breaking things. So at the Draco home, it was such an emergency that they called 911 and had him taken away. Of course no one ever takes it seriously when he does the same thing at his parents or sister's homes. We have been pleading for help. Our firm plan is to get him settled at the Abilene State Supported Living Center. It will be a great community for him on his good days, but also equipped to care for him on his bad days.

Back in February, Jay was becoming too violent to live at home. We had taken him out of the previous group home, Daybreak - the one with the staff who fed him junk food, taught him to like Eminem, and took him to a strip club - and hoped it would work out. When it didn't, we requested ASSLC, but no, the Betty Hardwick people said they wouldn't likely take him, and insisted we put him in another group home first. So Jay went to Draco, where they gave up after one week.

Yes, one week. We told them exactly what his behaviors are. They were sure it would be no problem.

They're professionals, right? After a week, my parents got a call from Draco: Either come get Jay or we'll calling to police to come get him. My parents immediately picked him up. Later, we learned that what they did was illegal; they can't deny him service. If the residence he was in wasn't appropriate, they are required to create another place to accommodate him. But they didn't, we didn't know the rules, and the people at the Betty Hardwick Center found it convenient not to inform us, and they didn't make Draco comply. So Jay came back to his parents' house to live, and Betty Hardwick caseworkers assured us that they would get him another placement soon, and also start the paperwork for ASSLC.

Almost three months later, my parents are exhausted. My Mom had a fall last weekend, and we realized immediately that she was no longer capable of taking care of Jay - something that is difficult even for a young, energetic person. My Mom has post-polio syndrome, arthritis, and various other ailments that make any kind of work difficult. But no one took us seriously when we said it was a real emergency - Jay needed a place. I'm sure many at Betty Hardwick Center and Draco were upset with us by the time we pestered them enough to get him back into a group home. My Dad called Austin - the Department of Aging and Disability Services - and finally someone there set things in motion.

How soon, we asked, would the ASSLC make a decision? We became more frustrated when we learned that the Betty Hardwick people had not even sent over Jay's paperwork. They were (still are) waiting for medical records. But as the secretary at the doctor's office said, she's not superwoman! She can't make all those copies and get them sent off, even though it's important. Of course not - how many months ago were they requested again?

We are so tired of bureaucracy. So tired of slick talking caseworkers. So weary of getting different information from every person we talk to. So frustrated by people who don't care, don't do a good job, don't want to be bothered. Red tape, hurdles and hoops and loopholes. People telling my parents that they're just trying to protect Jay's rights - as if my parents don't care about him. If we didn't care about him, we wouldn't ache for him so much - it's difficult for all of us, but Jay is absolutely the one suffering the most.