

At least the barbed wire has gone now!

Bob Lee

Many years ago I was visiting a friend in the small room (more of a cubicle really) he occupied in a nursing home. It was quite a momentous day. It was the last day he was to spend in the institution he had endured for much of his life. We were quietly talking about all the things he would soon be able to do which were not now possible. Not very radical really, not even irresponsible! Just some of the things you can do in your own home. Things like... sleeping in on the weekend, staying up late at night, eating between meals, having a friend over for coffee or a meal, having a garden, and maybe even having a pet cat!

Just as we were getting a little more ambitious with the expectations, some new faces appeared at the door. It was a group of concerned looking people arriving to say farewellwell not really. We all knew that it was a last ditch effort to talk him out of moving. The leader of the group shuffled in as I shuffled out to make room. She loudly exclaimed about the "lovely" room and said the fatal words "I don't know why you want to leave here. I'd be happy to live in a room like this!"

I will never forget the next few moments. He was always so quick to spell out his words on his communication board. This time however he took his time, taking great care to ensure that his response was clearly understood. "GOODYOU CAN HAVE IT. ...!M MOVING OUT TOMORROW!

During the rather strained silence which followed this exchange, I reflected yet again on the tension which always seems to exist between two quite legitimate concerns involving people with disability. On one hand there are those whose primary concern is for the safety and security of vulnerable people, and on the other there are those who struggle to assert their legitimate rights to have a regular life as part of their community. Why is it that these things are thought to be incompatible? ·

There is no mystery about how most Australians like to live. We are surrounded by the evidence. We like to live in houses, or in apartments. Some of us like to live with our families, or with friends, and some of us like to live alone. Some of us like to live in very isolated places, but only a very few. Most of us like to be close to other people as long as we have a little privacy, independence and autonomy. Sometimes we dream of having a farm, a mountain retreat, a penthouse, a beach house, or a boathouse. I've never heard of anyone dreaming of having a bed in an institutional dormitory.

In fact despite the commonly stated belief that institutions offer safety, security and efficiency, they are unlikely to ever be accepted as a mainstream accommodation option. Most of us willfully refuse to move into one until we are old and no longer capable of resisting the concerted efforts of well-intentioned family and medical systems.

Why do we resist? Well it is probably because, whatever we would like to believe, we know deep down that safety, security and efficiency is not provided by buildings. We know we might be trading off our cherished privacy and autonomy for promises which can't be kept.

Those of us who take notice of the reports of abuse and neglect which occurs all too regularly in nursing homes, hostels and institutions for people with disability, know that these can be dangerous places for vulnerable people. I once visited a "homeless" shelter where people paid the fee for a bed so they could have access to a bathroom, but preferred to sleep outside where it was safer.

So what about those people with disability who have found a place for themselves in the community? Those places are just as we would expect. Houses and apartments, shared and single, owned and rented. Life is also as we would expect. There's pleasure and pain, excitement and tedium, friendship and loneliness, gains and losses ...in other words, a regular life.

Some people have found they need a little more support than they get. Others find that they need less. Often surprising things happen. When two people go out together, have a meal together, a cuppa together, laugh together, the barriers between worker and client dissolve and they become just two people enjoying life. Other barriers just don't get constructed in the first place .

People have found that safety and security comes from knowing the neighbours, having friends and family who visit, and being part of a community whose eyes are watching what happens. A community which has a belief that people with disability should be treated with respect and given a fair go, will not tolerate the abuse, neglect and exploitation of those who are vulnerable.

Nothing has moved me so much as seeing the unrestrained weeping and inconsolable grief of a man who asks what it was that he did wrong to be moved to an institution six hundred miles away from his family home where he has lived as part of a loving family for forty years. What possible answer could soften the rejection this man feels?

Those who are wondering about my choice of the title of this piece can now be enlightened. A few years ago I was visiting a man who lived in an institution. He was a quiet, gentle person who liked to sit in the sun. He was placed in the institution by family members who were reassured by the talk about the place being "just like a big family." As we sat together one fine morning I asked him how he liked living there. He glanced up at the two metre high chain wire fence with the three metre high posts surrounding the building and said.... "Well at least the barbed wire has gone now!"



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