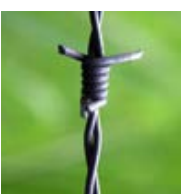


AT LEAST THE BARB WIRE HAS GONE NOW

by Bob Lee

Bob Lee lives and works on the Sunshine Coast. In this article, he draws on his extensive experience in the lives of people with disabilities as a service worker originally and as the Coordinator for the local Citizen Advocacy Program in more recent times.

This article was originally published in CRUCIAL Times, March 2008, Issue 40. Community Resource Unit: Brisbane.



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

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. "GOOD ... YOU CAN HAVE IT ... I'M MOVING OUT TOMORROW!"

"I don't know why you want to leave here. I'd be happy to live in a room like this!"

During the rather strained silence which followed, this exchange,

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.

I reflected yet again on the tension which always seems to exist between two genuine concerns involving people with a 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 are struggling to assert their legitimate rights to have a regular life as part of their community. This tension is perhaps most obvious in the continuing passionate discussions about where and how people with a disability should live.

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a disability should live.

Like many others who were living in institutions because there were simply no other options, my friend moved out and made a home for himself with the support of family, friends, and newly

employed paid workers. He, like those who had gone before, found that far from being hostile and dangerous, the community was in fact welcoming, accepting and determined that people with disability should have a fair go in life. He found that his

neighbours, local shopkeepers and others he met in his new neighbourhood were quite willing to offer advice and assistance without having to be paid, and to his great delight he found someone who shared his love of gardening.

Those who are planning for the future are often convinced that a choice between group home or living in a real home means choosing either the safety, security and supervision of an institutional model, or the risk taking and unknown dangers of ordinary community living. Many of those who live or have once lived in institutional places will remember their own experiences and react with laughter, sorrow, or abiding anger at this deeply flawed thinking. Such thinking ignores the existence of the routine humiliations, and regular incidents of abuse and neglect which continue

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Some people with a disability who employed students as support workers now have lifelong friends who are doctors, lawyers, journalists, movers and shakers. In other words ... friends in high places.

Perhaps most welcome of all was the unexpected sense of safety and security he

came to enjoy. He had anticipated, because he had been relentlessly warned, that the cost of gaining some independence, autonomy and privacy was that he would no longer

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Nothing has moved me so much as seeing the unrestrained, inconsolable grief of a man who asked me what it was that he did wrong, to

be moved to an institution six hundred miles away from his family home where he had lived as part of a loving family for forty years. This man needs more than an explanation. He needs to go home. He needs to have the opportunity to live close to his family and

and given a fair go, will simply not tolerate the abuse, neglect and exploitation of those who are vulnerable.

I have never met anyone who was placed in an institution because those who did the placing wanted them harmed. The motivation is most often about

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safety, security, professional care, and ‘peace of mind.’

Unfortunately, when isolation, rejection, abuse and neglect comes along as part of the bargain, peace of mind gets considerably diminished.

We all need to resist the temptation to associate the strong walls of institutions with protection from harm. We need to resist the temptation of seeing the congregation of people with disability as anything like family life.

Perhaps if we listened a little more carefully to those with personal experience of institution or group home living, then we could do more to avoid the unintended consequences of our good intentions. Recently, I found myself at another institution visiting a man who had lived there for many years. 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 ... ‘at least the barbed wire has gone now.’

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People have found that really effective 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

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