

This is not to say that staff were awful, though some were, and we were often frustrated by our lack of power in keeping good ones and getting rid of bad ones. So often, someone who worked really well with our family members would suddenly be moved somewhere else, sometimes because their skills were seriously needed elsewhere to put out fires. Sometimes it was just to remind all of us that we shouldn't get too comfortable and make emotional attachments. My heart broke many times over the years when someone Indigo had grown to love – and heaven knows this was a hard thing for him to do or to understand – would suddenly disappear completely from his life. No wonder he gets jumpy if I go away for more than a couple of weeks.

One of the joys of an independent life in our community for Indigo is that he now has some control over keeping relationships going with staff who have moved on for one reason or another. One beautiful young woman stopped working with Indigo, to have a baby, but she is still part of our family. To ask to see someone who has been a personal assistant and to be able to invite them over for a barbecue or even to visit them in their own homes is, well, normal, and nice. Yes, this really crosses the barrier between 'worker', not taking your 'work' home, and friend, but I value this deeply.

For many years, Indigo was on a housing waiting list for a transfer to the region where we live. Nothing was happening and nothing was likely to happen. "Heck," we were told, "he had accommodation; what more could you want for him? Consider the needs of all the others out

there." However, an incident of abuse brought things to a head and it was decided that he would be safer near his advocates, his family.

So began the long search for someone to share with and somewhere to live. This would be the only way we could make his funding stretch, we were told. But we realised that to share with another person with a disability would put us straight back into being powerless in another mini-institution, albeit nearer to home. However, we did meet some very good people through this process, who are now part of our broader community.

When Indigo was allocated a unit through public housing, it was time for the disability support funder to match its own claims. It said it believed in individual responses, but this required them to 'unbundle' funds from a block-funded arrangement. This proved to be sticky, but eventually my husband's reasoned arguments and my pig-headed determination led to the right thing being done for this young man.

Indigo now has the best possible chance for the best possible life he can lead, and I am well satisfied with that. In his own home, he is not told "don't." Staff think carefully about the words they choose. He is shown what he needs to do, so that he learns more control.

Every time he, his staff and I walk into his lovely, calm, open and welcoming home, we all feel good. This life bears no comparison to the one he had before.

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Segregation and Congregation and the Gaining of a Real Home

Bob Jackson

Dr Bob Jackson is a well-respected consultant from Perth (WA) who draws on 30 years experience in human services and education in writing this article, which critiques the limits of group homes.

The pull of a group home has always been very strong for many families who have been counselled for decades by professionals that this was the optimum placement for their son or

daughter. The appealing promise of a group home was that they would be included in the community but looked after by staff, and so be safe from exploitation and harm.

Group homes attempted to address the many shortfalls of institutional life. Research over several decades that compared quality in institutions versus group homes has shown that large institutions reach only 10% of the maximum score when objectively evaluated. On balance, they do much more harm than good. In comparison, similar research on community housing (that is, group homes and similar arrangements) shows that they often reach 'acceptable' levels where the balance of harm and benefit to individuals is approximately equal. In fact, when the number of people in a group home is three or fewer, the probability of a positive score goes up considerably, but still falls far short of the 'ordinary life' achieved by others in the community.

In considering the problems with group homes, it is worth thinking about the implicit assumptions that they embody. Their presence implies that people with a disability should be congregated 'with their own kind', that general members of the community would not choose to share their lives with people with a disability, that the support provided needs to be paid rather than freely given, and the needs of people with a disability are less than other members of the community.

On this last point, general community members' lives are rich with valued roles, have considerable power in decisions such as who they live with and where they live, enjoy a positive reputation in the community, are filled with challenge and growth, and the home is the launching pad to a rich and valued life. It is unlikely that anyone would claim that a group home achieves anything like this ordinary life and research on the outcomes of group homes supports this.

To be included or belong in the community one needs to be there, to be socially participating, to have valued roles and the skills to be in those roles, to have learning opportunities, to have a positive reputation, to have a positive view about oneself, and to be surrounded by positive expectations by others. A group home allows one to be 'in' the community, but not necessarily 'of' the community.

To be congregated with three or more other people with a disability has several consequences. It is telling the community that

the most important aspect that they should notice about you is your disability – why else would you have been put together on that basis?

As disability is a devalued characteristic, the grouping of people on the basis of impairments heightens the likelihood of rejection and avoidance by others, whereas one person with a disability living with one or more valued community members would be much

more likely to be engaged and included.

Being grouped with other people with a disability almost certainly means that the available role models are also deficient in skills. We know that when we are surrounded by others of equal or lesser skill level our skills do not develop as well as when we are surrounded by more competent models to copy and be inspired by. Also, the expectations of staff working with the group tend to be 'disability related' rather than reaching for community level expectations.

Even worse, disability groupings can cause major loss of skills because the service is geared to the lowest common denominator. For example, all are locked in because one person wanders, or all are kept home because of the antisocial behaviour of one individual.

It is very difficult not to cause a community reaction of fear and avoidance when four or more people with disabilities are supported in a group in the community, even when there is no difficult behaviour in the group. Neighbours are not likely to invite four or more people with a disability as well as staff to a BBQ or neighbourly events. In fact, the reaction to a group home opening is often one of hostility, whereas one person with a disability moving in next door is likely to be accepted and even welcomed.

Overall then, the group home continues the processes of the institution in many ways. The congregation of people by disability is highly likely to cause rejection as it causes focus on this devalued characteristic and so feeds the stereotypes that exist. It continues the problems of loss of control over major life decisions, vulnerability to unreasonable demands of staff, stereotyping around negative roles such as incompetent or childlike, low expectations, and lack of community belonging. If we think of the goal of an ordinary life – and surely that is not an

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unreasonable goal – then it is clear that the group home model will have great difficulty making this a reality.

We now have many examples of people who, in their own homes, in work places and in other places in ordinary life, have made substantial gains in their development. They are surrounded by more competent role models and normative expectations that do not seem to occur in disability groupings.

All around the world we see people achieving an ordinary life in the community with natural support from ordinary members of the community. I cannot believe that we are incapable of achieving what others have managed. We need to start with the will to try for an ordinary life. Then with creativity and focus on what is ordinary and valued, we can start to build ordinary lives for people who will otherwise continue to exist in lonely and unstimulating environment.

AT LEAST THE BARBED WIRE HAS GONE NOW

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.

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 farewell ... well 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. "GOOD ... YOU CAN HAVE IT ... I'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 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.

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.

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