

CRU's President's Report

What Makes home 'home'?

Welcome to this place of reflection about home. I would like to make some personal reflections about home and explain briefly why it has become so pivotal in my life over the years. To set the scene: as a child I was raised by my parents in an old Queenslander house – for me this really was home. Then, through necessity, I put myself into an institution – certainly not my idea of home. After my escape from the institution, I lived for a number of years in several group-share homes. These weren't too bad, but now I'm living in my own inner city unit – a place I really call home.

It appears that most species need and have a shelter, but for we humans it has to be much more than just cover. It's a place where we find rejuvenation, a sense of being, and a sense of our true selves without experiencing the scrutiny, interference, or criticism of others. We are even free to sit around in the nude, if we so desire, without offending anyone (unless it's a shared situation). At home, one has control of one's own immediate environment. The notion of 'King of the castle' exists because it speaks to people's reality.

As someone who has a disability, my home is most important to me, dare I say even more important than it might be for some other people who do not share the vulnerabilities of many people with disabilities. Maybe this is because there are numerous situations where I feel disempowered, disenfranchised and oppressed. But in my own home I feel in control.

Another dimension to living in my own home is the need to keep a watchful eye on the maintenance and general upkeep of my home. This is a far cry from living in the institution or service run facilities. It serves as a good reminder that I am living an ordinary life, even if it's a chore at times.

I mentioned before the joy of having control. Having control over one's home is under threat for many people. The sanctity of one's home can easily be transgressed by service workers, visitors and even by well-meaning strangers. A simple example occurs when a worker has a key to the person's home, and uses that key to enter, without even knocking. For some people, there may be very good practical reasons for this. Nevertheless, there is an impact on the spirit of home. People experience a change of feeling as suddenly the person's home becomes a 'facility'. It is also too easy these days for one's home to become a place where Work-based health and Safety take prominence.

Although I definitely wouldn't swap my situation for the world, to say things are easy all of the time would be an overstatement. Firstly, it's difficult to 'fly solo'. One of the challenges for people living alone is of course the potential for loneliness. Please do not misunderstand me. I don't mean that all people with disabilities should live together. I am simply observing that periodic loneliness is a by-product of living alone and that one needs to find ways to have people in one's life.

There is also a practical problem. One has to ask for help as there's nobody there to give incidental assistance, and this takes courage. It means putting oneself regularly in the role of dependant and this is not an easy position to be in. So, what can one do for company? I refer to unpaid company, freely given relationships, not paid workers. This is an ongoing challenge for not only the individual, but also for the people who support that individual.

There are broad implications that flow from these brief observations. We must get much smarter and more diligent at providing people with disabilities with the most appropriate supports so that we can live

meaningful lives in the community. We must gain a better understanding about what it takes to live in the community. The service and its workers may not appreciate that what they are doing is supporting someone to have their own home. This can deteriorate to a situation of passive 'community minding'; that is, minding someone in their own four walls.

We need to understand that the role of the worker is in the context of helping people to make their home comfortable, meaningful and authentic for that person. Home is part of the person's identity, and the person's identity is expressed through home.

Mike Duggan.