

**Submission to the Senate Community Affairs Inquiry into the
“Adequacy of existing residential care arrangements available for
young people with severe physical, mental or intellectual
disabilities in Australia”**

By:

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Signed:

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Date:

**SUBMISSION TO PARLIAMENTARY ENQUIRY INTO THE ADEQUACY OF
EXISTING RESIDENTIAL CARE ARRANGEMENTS AVAILABLE FOR
YOUNG PEOPLE WITH SEVERE PHYSICAL, MENTAL OR INTELLECTUAL
DISABILITIES IN AUSTRALIA.**

My brother was injured in battle in Vietnam in 1968. Shrapnel entered his brain and fragments remained there causing scar tissue and more damage over many years. His life was saved because of the intervention of his fellow soldiers, treatment at an American M.A.S.H. unit, and surgery in a U.S. hospital in Japan. The miracle of his survival has been told a number of times. What is less well known is the tragedy of the following 40 years of his life.

He returned to an Australia where people with such traumatic injuries rarely survived. He was given a “rehabilitation” program at Heidelberg Hospital, was discharged from the army, and his family were expected to care for him. He had total paralysis on his left side and partial on his right, and his speech and ability to communicate were damaged. From being a strong, happy and well-liked, independent young man, a university student doing law and working part-time in the public service, he became obsessive, angry, frustrated, and ready to fight tooth and nail for some, any, level of independence. He struggled for years to get on to his feet, but finally had to succumb to full-time in a wheelchair, constantly frustrated by what to him was a total loss of dignity. His pride and sense of independence drove him to achieve much, but all his life he was ahead of his time, with the knowledge of brain injury and its treatment slowly gaining momentum but too late to give him the intervention vital for good recovery.

He was in and out of Heidelberg Hospital for years, spent disastrous time in nursing homes, and finally his efforts to fight for his dignity led to his being labelled psychotic and he was sent to McLeod Psychiatric Hospital and finally Bundoora Hospital where he lived for some years with the frail, elderly veterans of the second world war. He continued to fight to be heard and the other inmates reported to his family just how cruelly he was treated. It wasn't until 1990 that he moved to a long-term accommodation facility where care and rehabilitation was more humane and appropriate, and where gradually he started to respond to treatment which identified his needs and recognised his tremendous pride. But it was still an institution. He did not identify with the other disabled people, refused to be treated in group situations, preferring mostly to find a spot in the grounds where he could smoke incessantly and watch. There were too many patients/inmates/residents, too many people in uniforms and white coats.

In 2000, we stumbled across the option of small-group housing for people with disabilities initiated by the Victorian Dept of Community Services, and found a place for him in a unique house, purpose-built for 6 residents and managed by Yooralla. The house had/has large, airy rooms with en suite bathrooms, each with small private garden attached. We found an appropriately trained case manager and Veterans Affairs paid her salary. His savings purchased the latest wheelchair and an adapted car/van to allow him to be taken wherever he wished.

For the last 11 years of his life, he saw himself in a near-normal situation, meals cooked in a home kitchen, clean, modern surroundings where he could have friends visit, carers who for the most part had reasonable basic training, and who could be supported by his case manager to ensure he gained the help which suited him best.

During the greater part of his life after injury, my brother rejected his family's help, which he saw as interference. The saddest thing though was that he also refused to associate with his army mates. He just couldn't abide having them see him surrounded by elderly and/or disabled people in institutional atmospheres. He made this plain by shouting at them when they visited, by putting his head down and refusing – for hours at a time - to make eye contact, or by appearing to go into catatonic states, sometimes caused by epilepsy, but sometimes I am sure he induced and feigned himself (I have no proof, I just KNOW).

This all changed when he moved into the Yooralla house. He recognised and embraced the fact that part of the house was his. He chose the colour scheme and furniture for his small apartment. He zealously guarded the upkeep of his garden, refusing to allow family to work – or even sit - in it. He chose his carers, making life impossible for those he did not like, and responding with great affection to the ones he approved of, and enlightened managers – for the most part – tolerated this and rostered accordingly! He came to know the other 5 residents and sometimes took himself to the common living area, always making it quite clear who should sit near him – and who shouldn't. He always railed against family members, particularly if we encroached on his private quarters, but he would allow us to visit in the neutral living area of the house, and it helped him to finally accept he needed our “interference”.

It was this ownership and acceptance of his living situation, and his obvious approval of the near-normal living conditions, that finally allowed him a measure of happiness. His army mates became frequent visitors. They had always despaired, seeing him in degrading, institutional settings. Even at the more enlightened institution for brain-injured people, they responded to his perception of the place, and they hated it as he did. Having him properly – appropriately - housed helped them address their own demons and some of their collective anger towards the unfairness and randomness of my brother's injury and their survivor guilt. After moving to the house he began to accept their visits and it became a “normal”, friendly place for them, with my brother almost happy, almost accepting of his lot. He started to go with them to the RSL regularly. He became another “Old Digger”, with a place of his own to go back to, life he could keep private in comfortable living surroundings, a home of his own.

The development and maintenance of these small-group houses is very costly. However, there are many different ways they could be financed if lateral thinking is allowed to prevail, and individuals and the community has the support and advice to investigate. Economics should find a way instead of being the stumbling block.

People with severe and multiple disabilities obviously need a wide range of intensive supports, which have to be delivered inevitably by invading personal space. By ensuring the design of buildings and service delivery is kept on a “human scale”, and that each and every person, despite numerous problems and issues, will have **PRIVACY** – in essence a bolt-hole; **DIGNITY** – a place where he/she has control and finds comfort and relaxation; and **RESPECT** – a place clearly identified as being the domain of that person and therefore others cannot encroach without permission – society will come close to finding the best possible outcome for housing for people with severe disabilities.

Geraldine Colson
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