



29 July 2004

The Secretary  
Senate Community Affairs References Committee  
Suite S1 59  
Parliament House  
Canberra ACT 2600

Dear Senate Committee,

My submission is relation to 'Terms of Reference of the Inquiry' part 'C'.

My son Matthew is, at present, 26 years of age and the father of a four-year-old child. At the age of 22, Matthew found himself suffering from depression after a break down in his relationship. During this emotionally challenging time, Matthew made an attempt to take his own life by hanging himself at our family home. Our eldest son found Matthew and managed to save his life, however, Matthew acquired a brain injury.

For the next 17 months Matthew was a patient at the Liverpool Hospital/Brain Injury Unit. My wife and I also spent each day in the Hospital to assist with his rehabilitation program including physiotherapy and speech therapy.

Prior to Matthew leaving Hospital, staff recommended that due to his high caring needs he should be placed in a Nursing Home. We were urged he should be placed at Carrington Nursing Home at Camden.

My wife and I visited Carrington, which was built in the early part of last century; the home was very cold and uninviting with no view. Matthew would have been accommodated with two other young people with brain injuries and three old patients suffering from dementia, one elderly lady was calling out and crying uncontrollably. The room was very enclosed with high ceilings. Had Matthew been housed in this institution it would have had a detrimental effect on his well being and would have regressed in his progress due to the lack of a stimulating environment. The visit was totally depressing for my wife and I especially seeing the age of the caring staff, all would have been in the fifty plus age group and that factor would inhibit his rehabilitation.

I have heard the expression Nursing Home are 'Gods waiting Rooms' for young disabled persons they will be waiting for a very long time. From the enquires I conducted there are no group homes where young people with severe brain injuries can be lodged together.

There must be many thousands of young people with brain injuries and other types of disabilities in Matthews's situation. With the present number of car accidents there are likely to be many more looking for accommodation.

My inquiries have established that a considerable number of young people with disabilities, particularly with brain injuries die prematurely in nursing homes, I believe lack of compassionate nursing staff is one of the major contributing factors to this.

After two visits to the Carrington Nursing home I decided it was not an appropriate place for my son. The is not quality of life for a young disabled person in a Nursing home nor are there equal opportunities.

Matthew has very high caring needs, he does not walk, he cannot dress himself, nor can he feed himself or clean his teeth or take his medication, and he is incontinent. He is totally dependent on people, 24 hours a day.

As a consequence of this situation I retired from the workforce at the age of 55 years, living on my savings I renovated my car garage for Matthew to be self-contained and I currently care for him. Forced to make such a decision amid the severe depression I was suffering I was taken on a roller coaster to hell.

Initially after Matthew came home we received a 14 hour per week care package from Homecare, those hours have slightly increased, but its still a fight every three months when I have to compile an eight page submission to obtain carer hours from the State Government.

The carers who first came to the home were all above the age of fifty years old. They were great cleaners with reasonable personal carers, however faced significant barriers when communicating with Matthew due to the age difference. In his frustration Matthew's behaviour deteriorated; he was screaming and swearing, throwing himself around, not to mention the physical assaults on these aged cares. As a result I requested a behavioural management plan from the staff at Liverpool Hospital. The plan was a disaster; nothing changed with those carers.

I eventually made the decision to change the age of the cares and the company to Northcott Society. They supplied young male and female persons, most doing tertiary studies. After a short time Matthew's behaviour change dramatically, I now have no problems with his behaviour. Had he been in a Nursing Home he would have been uncontrollable. In that situation he would have been 'drugged to the hilt' to control him.

We are pleased that we made the decision to bring Matthew home. We can help with his daily rehabilitation program and he has improved dramatically, even though he is still dependent on us and carers for everything, his quality of life have improved. We are lucky that he has been able to access day programs through Disabled Service Australia and Myrtle Cottage a locally run disability service.

We take him on holidays, snow skiing with the NSW Sports Council for the Disabled. He goes to the body massages; hydrotherapy and anything that we feel will benefit him. We know he would not have had those opportunities in a nursing home.

Our biggest concern now, is the realisation of a future where we will not be able to care for Matthew because of our age or ill health. Under the present structure Matthew will mostly likely be placed into an institution such as a Nursing home. This is a distressing outcome for Matthew as well as his family.

Disabled young persons need accommodation where all young persons are housed together in-group homes with carers of their age.

I would be only too willing to give evidence at a public hearing.

Thankyou for reading my submission.

Yours faithfully



John Elleray.

