My name is Joan, and my husband John has an Acquired Brain Injury (ABI) as a result of a hypoxic incident after a cardiac arrest. It was April 2005 and he was 47 years old.

As a result of the cardiac arrest, John was in a coma for approximately four weeks which he spent in intensive care. The doctors were concerned about his future should he regain consciousness from the coma, they warned me that he would probably remain in a vegetative state.

When he regained consciousness, the doctors diagnosed him as having a severe ABI. They said he would need high- level care that was only provided in a nursing home. At the time, this was the only option presented by the hospital.

Finding a nursing home that would accept John was an arduous task, as most nursing homes don’t like taking in younger people. John then went two interim care units for almost a year, before being accepted in a nursing home where he stayed for two years. During the time John was in interim care, after much lobbying, he received a Slow to Recover package (A DHS funded intitiative). This meant that he had a case manager and access to therapies. This package is reducing. Recently, he also received an Individual Support Package.

After two years of living in a nursing home, John was involved in the My Future My Choice (MFMC) initiative, and was offered a place in one of the pilot shared supported accommodation facilities. This is where he is currently residing.

I am writing this submission in the hope that John continues to receive funding to ensure he has appropriate accommodation and support to meet his changing needs.

Term of Reference (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

Interim Care

John was in interim care for approximately one year after his release from the hospital, where he had been in intensive care for over a month and in general care for six weeks. I could write a whole book on the lack of adequate care that was available at the two interim care units John resided in during that year. Both were horrible places. Every day that John was there was a nightmare for me because of the lack of care provided in both places. I am appalled that the managers of both places are allowed to run a business the way they did. They are in the business of caring for people; they are making money out of it, but they are not really responding to their real mission.

When John was placed in interim care, I didn't feel I had any other options, as no nursing home had offered John a place. I would spend as much time as I could with John; I would race to the unit from work and be there every night and every weekend. I didn't have a life at all. I subsequently was diagnosed with a serious illness, and the stress of caring for John knowing he was in an inadequate facility definitely caused that illness.

An example of the total misunderstandings that can occur in facilities that are meant to care for people with disabilities was the first time I visited John in interim care.

When I arrived, I rang the bell and entered the building. I had raced in from work because the hospital had said John was moving to a nursing home. I didn't have a choice in where he was going, as once the hospital decide they need a bed, you just have to obey their choices. As I entered, I asked the receptionist if she could direct me to my husband's room. She was very rude and said, "We don't deal with that part of the nursing home, ask the nurse". I went and found the nurse and said, "Where is my husband's room?" and she went from door to door calling out, "Is John Carpenter there?" This was very embarrassing, because there were people in the room and most of them were quite ill, so I felt it was very disturbing for them.

After we went to several rooms, the nurse insisted that an elderly man lying on a mattress on the floor was my husband. When I saw this man I couldn't believe that my husband had aged thirty years from when I seen him the night before. I said, "I don't think this is the right room, can you look on your list?" Finally we found John and he was lying in bed, soaking wet. The hospital hadn't told me to bring a change of clothes for him, and there were no clothes available at the interim care unit. I raced home and got spare clothes. It was one of the hardest experiences I have had since my husband was first in critical care.

Another example of the inappropriateness of the interim care was their inability to keep residents safe. One night (approximately 7:30pm) I got a phone call from a stranger in the community (two kilometres away from the interim unit) who told me that he had found John on his nature strip with a bleeding head. Fortunately, John was able to remember my phone number, and the man called me and an ambulance (because John was bleeding quite badly). I said to the man, “Can you ring the interim care unit?” I just couldn’t ring them. He rang me back and told me that they didn’t even know that John was missing. Imagine my surprise when the interim care unit, where I thought my husband was safe and secure, were totally unaware of his absence and the risks posed to him. They never, ever apologised that this happened.

At the interim care unit, the staff weren’t empathic or understanding of the needs of a person with a brain injury. The staff are supposed to care for the residents, but I wouldn’t even want to use the word “care” as a descriptor of their role. It was so horrible.

After much searching for an appropriate nursing home, John was offered a place at a residential aged care unit. I was relieved, because finally I had succeeded in moving John somewhere more permanent.

Nursing Home

John lived in a nursing home for approximately two years from 2006-2008. In my opinion, the nursing home was much better than interim care. The manager was more in-tune with the needs of the residents, and the staff were more caring and compassionate.

In saying that, a nursing home was not an appropriate place for John. He was much younger than the other residents, and the debilitating nature of his brain injury was different to the needs of other residents. Due to the deficits in his short term memory, John didn't know why he was there and he constantly walked around in an agitated state. Due to him being so tall, the female residents in the nursing home would get frightened of his height. This wasn't their fault, but also wasn't John's.

a) Staff and facilities

The staff were beautiful. They were caring towards me and towards John. The manager was quite strict about her staff and how they treated the residents. It was a major difference to interim care.

The staff included John in activities at the nursing home, and these occurred daily. To some extent, the activities were suitable for John, for example, he enjoyed crossword puzzles and quizzes. The nursing home was one of the few nursing homes that was innovative and creative in their diversional programs and tried to match the activities to the needs of the residents.

Although the care at the nursing home was more appropriate, the staff weren’t trained to deal with brain injury, and the facilities weren’t compatible with John’s needs.

An example of this was trying to manage John’s tendency to abscond. John’s neuropsychologist suggested putting a tracking device on his wrist, however, the nursing home didn’t have the facilities on their computer system for the tracking system to operate. They said they would need to change their whole computer system, which was not financially feasible.

Although the staff were caring and did the best they could, the ratio of staff to residents was low, and they could not provide him with one-on-one support which hindered his recovery. For example, staff would dress him even though he could dress himself. He would take a long time, and you needed to prompt him, but staff didn't have this time. Staff are given a certain amount of time to do each task, therefore they have time limitations.

Because of the staff to residents' ratio, in some ways they weren't available to adequately address therapeutic needs of John, e.g. they couldn't do his exercises with him.

b) Building structure

Many nursing homes have glass doors at the entrance, and chairs near the entrance. For John with his brain injury, and for many other residents, it was stimulating to sit in front of the door and watch it open and close, wanting to leave too. John would think, "Everyone is going out, I want to go out too”. For people with a tendency to abscond, this is a serious safety issue.

The long corridors in the nursing home also weren’t suitable for John. His short term memory deficits made it very difficult for him to find his room, and he would get agitated and confused.

Nursing homes are also always noisy and for people with ABI, noise is quite debilitating and fatiguing.

c) Legislation

As noted above, John has no short term memory, so he couldn’t find his room in the large nursing home. His Neuropsychologist suggested that he should have his photo and name on his door. The manager felt that it was against legislation regarding the privacy of the residents to have their name on their door. This is a perfect of example of where legislation doesn’t match the needs of the person, particularly when they have a disability. There needs to be flexibility, as not all individuals fit into the same box.

Another example of how legislation impeded John's recovery was his limited access to the kitchen facilities for health and safety reasons. When his speech pathologist was training him in independent living activities, he wasn't able to use facilities in the kitchen, e.g. to make a cup of tea.

Sometimes legislation doesn't quite meet the needs for people with disability. There needs to be flexibility for the person to have choices. Nothing is ever quite concrete.

Term of Reference (i) what have you achieved by virtue of YPIRAC (MyFutureMyChoice) funding and what are you afraid of losing? OPTIONAL

In 2008 John was moved to a My Future My Choice (MFMC) home as an alternative to living in the nursing home.

Improvements from the nursing home

Living in the MFMC home is a more ideal situation because John has his own room, which he is allowed to have his name on, so he can find it. The home is much smaller; there are only six residents so John doesn't get confused. The ratio of staff to residents is much better and it is less noisy, so John doesn't get agitated. Also, the structure of the building allows for him to wear his tracking device on his wrist, meaning that when he gets close to the door, it beeps and the staff automatically lock the door so he can't abscond. This makes me feel a lot more comfortable, because I know that I am not going to get a phone call from someone in the public who has found John. The staff are also more equipped to deal with people with brain injury, because they get more training.

Things that could be improved further

Although this home is a vast improvement from both interim care and from the nursing home, there are still issues that could be ironed out.

For example, when homes are created it is important to respond to the needs of people with a disability. This includes, adequate and appropriate training for staff. Staff need to be carefully recruited to ensure they have a positive attitude to caring for people with disability.

This also includes the structure of the building meeting the needs of the people living there, for example, making sure corridors are wide and that there are measures in place for ensuring residents can't abscond.

Legislation needs to be flexible, and account for the differing needs of people with disabilities, for example, for some residents a kitchen may present some safety issues, however, for other residents who are developing their independent daily living skills, access to a kitchen is vital.

I also think that the organisations that manage the homes need to be more flexible and ready to meet the changing needs of people with disability. An example of a time when John's needs changed and some flexibility to deal with these needs was met with resistance when he had a bad fall two years ago. He was in hospital for weeks and although he could have been discharged, the house he was residing in wouldn't have him back because they didn't feel they could adequately deal with him. They wanted to send him back to the nursing home. After much discussion with DHS and the house, the house moved from a sleepover model to an active-night model and John returned to the house. This meant that if John woke up during the night, there would be a staff member to help him.

I am worried now, because the house want to change back to a sleepover model, and I am unsure that that will adequately meet John's night-time needs of staying safe.

My Ideal World

In my ideal world, John would live in a home similar to the one he is in now; small, bright and accessible and with other residents that he can interact positively with. He would be offered more one-on-one support that provided opportunities for him to engage in stimulating and interesting activities. The staff that would provide this support would be skilled, encouraging and enthusiastic. There would be room for flexibility as John's needs change and this flexibility would be met without resistance.

Hopefully legislation continues to meet the needs of people with disability, and allows John to receive the funding for the accommodation and support he needs. There needs to be flexibility for people with disability to have choices. Nothing is ever quite concrete.