Mrs J McRae

17 July, 2004

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

RE: SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE: INQUIRY INTO AGED CARE

This submission refers to the Senate Community Affairs References Committee Inquiry into Aged Care, in particular **Section (c) of the Terms of Reference**.

It has been difficult to separate all the issues my husband and I are facing in regard to his inappropriate nursing home placement. The first five pages of this submission give an outline of how the nursing home is impacting on our lives. There is also an attachment of 5 pages of correspondence to and from DADHC.

My husband, Mr Todd McRae, suffered from an extreme asthma attack, which resulted in a hypoxic brain injury in May 2002. He spent 8 months in Liverpool Brain Injury Unit (which is a unit dedicated to Traumatic Brain Injury). He then moved to Queen Victoria Memorial Home (an aged care facility) in January 2003. He is currently still in this facility. This event has left Todd severely disabled He is unable to speak, eat or move his body or limbs in a purposeful way. He is however quite aware and I am constantly working towards establishing communication. Todd is 32 years old.

Many of my concerns regarding Todd's care are directly affected by the funding and subsequent staffing ratio that the nursing home implements.

The fact that my husband is in a nursing home, affects both of us as a couple. I spend nearly every day with him and am constantly frustrated with the little or negligible care that he receives. The regular rotation of staff means that I have to repeat over and over, little things that I expect would be commonsense. "Please tell Todd what you are about to do to him, please position Todd so that his body and limbs are as aligned as possible." After eighteen months of this charade, I am still reluctant to have a "day off" as I worry about his emotional and physical wellbeing. It seems that the more I do, the more is expected of me. When I dare to inquire if Todd's teeth have been brushed this morning the reply is often "Oh, sorry, I forgot!"

In summer when the staff are hot from physical work, he is often sat under the air-conditioner in his room where his non-movement means that his feet feel like ice-blocks, but very few bother to check them.

Todd's basic requirements are met. He receives his nutrition via a peg-tube directly to his stomach. He gets to have a bath every second day. He is incontinent and gets to have his pad changed up to 3 times per day (all pad changes have to be documented to ensure they are not being wasted). If I were not there every day, Todd's day would consist of being got out of bed at about 11am. He is not a priority in the mornings as are other residents who require being up for mealtimes. Once in his wheelchair he would be left to stare at the four walls he has to call home or have the TV on to some show that he would never have watched eg Bert Newton, or played one of his CD's (possibly the same CD for 3-4 days). The afternoon staff come on and hurriedly try to get everyone back to bed again at 3pm before the dinner time rush.

He does have a swallow reflex, but this is quite slow at times and the staff does not have time to give Todd food orally.

Todd is extremely limited in his communication; he cannot speak but often cries out and moans. Different staff reacts in different ways to his calls for attention. One particular RN told me that after hearing Todd crying out for over an hour one morning, she had to direct staff to attend to Todd and try to re-position him to see if that would help, which it did. He is ignored and so are many of his needs, by people who are scared to treat him as a real person. His cries for attention are often deemed that he is in pain that requires Panadol. I believe that many staff think that quiet and drowsy residents are happy residents. People in residential facilities usually leave in a wooden box or ambulance. Occasionally one of the residents will wander into Todd's room and you can see quite clearly the look of fear and distress in his face and eyes. Friends are reluctant to visit an establishment where all the other elderly residents are wandering around in various stages of dementia or all lined up in the sitting room staring into space, so consequently he receives very few visitors. The only way he can access some normality of his former life is through me and my desire and ability to provide stimulating environments.

Physiotherapy is virtually non-existent. There is a physio assistant on duty for 5 half days per week and the qualified physio works one full day per week. When Todd first moved there I was told that they would try to see Todd 2 or 3 times per week. Their excuses for not finding any time for Todd, have been many and varied: Todd was still asleep at 10.30am and they didn't want to disturb him, Todd had serial plasters on his wrists for two months after botox injections and they didn't think he could tolerate additional stretches, they have 100 residents to look after and are very busy, communication problems with the community physio from the Brain Injury Unit, Todd is too busy with things that I do. All of these reasons were not discussed with me until I asked why. The assistant has blatantly said aloud while giving Todd his 5-minute session, that she is only doing it for hygiene and that Todd will not recover at all. How must that feel for him, that these people who are supposedly trying to help him, can offer their personal opinions in such a negative way.

The Diversional Therapy staff are also very busy. For the first six months that Todd was there, they managed to take he and I for 2 visits to the local botanical gardens. They had said that they would try to do it once a month but that didn't eventuate. In February last year I started taking Todd to a hydrotherapy pool once a week with the assistance of some friends, the closest one with the right temperature, hoist and change table is 50 kms away. The taxi voucher contribution of $30 would have equated to me having to pay the difference roughly $200 per day. The taxi company came to an arrangement that enabled us to do this without additional cost to me.

In March 2003, family and friends organised a fundraiser which paid for Todd's motorised wheelchair and in June 2003, we purchased a second hand van that had the disabled hoist. I was not going to have Todd sit in bed or an ill-fitting wheelchair for six to eight months waiting for his name to come up on the PADP list, and I found the wheelchair difficult to get up and down hills without the motor. Because he was a nursing home resident he was not a priority for PADP equipment. Since buying the van we are out and about at least 5 days per week. It makes it much easier to get Todd to appointments and hydrotherapy, but all these outings create other problems. There is only a 1 hour time slot in which disabled people are allowed to use the pool and this also has to be timed around another disabled young girl, as they both require use of the water access chair and both cannot use it at the same time. The physiotherapist, who runs the pool does not seem very understanding and if Todd is groaning, she feels embarrassed for her private clients, and offers that they should wait in another quiet room. This is accompanied by glares in our direction to the effect that our helper and myself feel very uncomfortable for disturbing her business. There is a whiteboard on the wall in Todd's room which I write down the following day's activities and what time Todd needs to be ready by. The constant changing or shortages of staff and staff forgetting to read these messages means that quite regularly, Todd is still in bed when I get there to pick him up.

For the past 7 months we have had regular articles in the local press, asking for volunteers to assist with passive body and limb movements. The responses were very positive and we now have about 15 people on board who visit Todd either at the nursing home or at our home on a regular basis. The constraints placed on volunteers in regard to getting criminal checks etc to satisfy OH&S requirements scared some of them off. The phrase that "Big Brother is watching you" was mentioned by a few and they did not return. Most of these people would rather do these exercises at our home, where the atmosphere is relaxed and quiet, without interruptions. Todd generally responds favorably to this stimulation and I'm sure that he enjoys being at home, if only for a few hours. Our weekly timetable is quite busy. I take Todd to a student "Uniclinic" at a local university 2 days per week for massage and osteo treatment. A private massage therapist also visits Todd once a week at the nursing home. This is paid for out of leftover fundraising monies and as such I don't know how long these therapies can continue. The need to constantly ask the same family and friends for "charity" is quite humiliating, but what choice do I have. Fundraising also has a limited life as other tragedies happen in everyone's lives, which take priority over our plight. In my wish to bring Todd home for sessions of exercise, the nursing home often has difficulty in getting Todd ready by the required time. Some of these sessions start at 9.30am so that we are not imposing too much on these volunteers and they do not have to give up their whole day. In accessing my husband to friendly and home environments, I constantly have to take into consideration the staffing of the nursing home.

While Todd was in the BIRU his rehabilitation consisted mainly of trying to slow down the muscle contractures that happened anyway. He generally received 3 physio sessions per week. This was not enough to have any great effect and because of the high demand for beds his discharge was in the planning stages 6 months from his injury. I truly wanted to bring Todd back to our home to live, but with a then 14 year old son about to enter year 10, and the house needing some minor modifications and equipment, I reluctantly accepted the offer of my 2nd choice for a nursing home close to our home. At that time I did not think that I could get by with 15 hours of home care per week without restricting my son and his needs. My first choice was a nursing home a little further away, but with a few other young brain injured persons as residents. 6 weeks after the application was lodged at this facility I was informed that they would be unable to accept Todd, due to funding and Todd's classification as "High Needs". So the fact that he has high needs, negates him from a place which actually has systems and therapies in place to deal with other young people classed as high needs.

Just before Todd was discharged from Liverpool Hospital, I had started to bring Todd home for overnight stays with the assistance of an attendant carer, supplied through the Carer Respite Centre. I had purchased a 2nd hand manual hospital bed from a nursing home and we were able to borrow the air pressure mattress and food pump from the hospital. I was responsible for Todd's feeding and medications and these visits went extremely well, Todd slept very well and seemed to enjoy being at home. To my dismay, I found that when Todd moved to the nursing home, he was ineligible for this service, as it is only available for people in the community. This is a criteria I have encountered many times over the past 18 months. It is very unfair that because he is deemed to have all his needs met by the nursing home, that we are unable to access some assistance to allow Todd to spend a night at home on a regular basis. I wrote to the minister of DADHC, Carmel Tebbutt in January 2003, explaining this situation and asking if there was some way to overcome this denial of service. I finally received a reply in September stating that they were aware of the difficulties experienced by young people residing in nursing homes but they were unable to assist. By the end of 2003 I was getting fed up with the whole nursing home situation and decided that I would plan to get Todd out and move him back to our home to live. I had heard about the "Attendant Carer Program", which offered up to 34 hrs per week of care and on my initial inquiry I was advised that one of the criteria was that the person be able to direct the carer's themselves. I expressed my frustration that this criteria would be difficult to meet, but was encouraged to submit an application anyway. The assessment for this service was conducted in April 2004 and as I had heard that additional funding was available for this particular care package, I was quietly optimistic that Todd would be accepted. I expected that I could direct the carer's on Todd's behalf and that we may have been able to interpret Todd's responses in the more relaxed home environment to at least try to give him the chance to have some choices in his daily living. At the nursing home he has NO CHOICES, everything is done TO him, with no regard as to how he feels about it. This submission has attached the subsequent correspondence to and from DADHC. It appears that because Todd has been classified as being eligible for nursing home placement, he is doomed to spend the rest of his life there. I believe that State and Federal government policies are part of this problem. Why would the state funded DADHC want to take on the cost of Todd's care, when he is currently being "looked after" by the federally funded nursing home. Because you are in one, excludes you from the other. Yet if Todd were at home he would be able to access respite care in a nursing home. As suggested in the letter from DADHC dated 24th May, I contacted Marie Jolley who gave me the phone numbers of a couple of Home Care Regional managers. Every person I spoke to passed the buck and told me to call someone else. I was eventually directed to call the general inquiry and assessment service. Thanks for nothing! The second letter's suggestions finally met with some success and I have been able to secure some short-term access to an overnight carer service for 3 overnight stays. The main part of this process is to trial having Todd at home and while I can manage his daytime needs, I need help to build my confidence and experience with turning him in bed.

State boundaries are also denying Todd access to a young persons group home in Canberra. Todd has been to the Dorothy Sales Cottages in Canberra twice this year for one and two weeks. Their caring manner, staff ratio and positive attitude in providing therapies, which have improved the quality of life for some of the residents, impressed me. Even though Todd is not strictly eligible for respite, they allowed him to stay there for the standard respite cost of $25 per night. Of course Todd's disability pension still went to the nursing home for these three weeks so that his bed was still there when he got back. I was inspired by the programs that they are providing and I have tried to implement some of their suggestions in exercises, eating orally and communicating. Todd seemed to respond to the staff who treat the residents with respect and not with the idea that there is NO HOPE. The ACT government has recently directed the Centacare run facility, that persons from NSW must now pay $3000 per week to stay there. They are not saying that NSW residents cannot use it, they are just putting it out of financial reach for all persons who have non-compensable injuries.

There are no options available to persons such as Todd and myself. The nursing home is not the right place for him to spend the rest of his life, possibly 40 years. I want to care for my husband at home and it seems ludicrous that beurocratic guidelines are denying us choices in this regard. In the long-term, there is a need for many more facilities like the one in Canberra, to stop persons like Todd from being imprisoned in establishments that have to meet budgets, and where the resident is little more than a number with a certain number of tasks to be attended to each day. State and Federal governments must jointly start implementing some changes to the system. The Federal response that the State is supposed to look after people with disabilities is not the answer. The Federal Government must take leadership in ensuring that these vulnerable members of our society are no longer ignored.

I am available for confirmation, discussion on any of these matters. Mrs Jacqueline (Jackie) McRae

Yours truly,

Jackie McRae