TO: The Secretary
The Senate Community Affairs
Reference Committee

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PART 2: SUBMISSION BY:

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INQUIRY INTO AGED CARE

PART (C)

"The appropriateness of young people with disabilities being accommodated in residential care facilities (nursing homes) and the extent to which residents with special needs, such as dementia, mental illness or specific conditions (e.g. Acquired Brain Injury) are met under current funding arrangements."

28th July 2004

SUMMARY

This submission is a personal document about a young woman, our daughter, who is presently residing in a Nursing Home after suffering from a Traumatic Brain Injury following a car accident.

I have addressed this submission in two ways; firstly as a mother and secondly from a professional perspective.

This submission includes:

- Background
- My daughter's Current Status
- My daughter's Perspective
- Mother's Perspective and Effect on Family
- Professional View
- 7 x Supporting Documents
    1. Poem
    2. People with Disabilities Australia Inc.
    3. Commissioner for Complaints
    4. Guardianship Tribunal
    5. Centrecare
    6. Registered Nurse
    7. Neurologist

BACKGROUND

Prior to our daughter's car accident, our knowledge of Nursing Homes was negligible. Now we are sad but committed and competent advocates for Young People in Nursing Homes.

Our daughter had a non-compensable car accident. She suffered Traumatic Brain Injury in December, 1999, aged 32 years and was unconscious, on life support in Royal North Shore Hospital, with a dubious prognosis. January 2000, still in a coma, she was transferred to the Brain Injury Unit, Royal Ryde Hospital, where she remained until her placement in a Nursing Home in January 2001. She was classified as a Category 1, 24 hour care resident. At that time she was:

- unable to speak but could give 'yes', 'no' indications,
- confined to bed or wheelchair,
- being fed by a P.E.G. tube through the abdominal wall into the stomach,
- incontinent of both urine and faeces,

and had –

- quite good long-term memory of her life and work prior to the accident,
- almost nil immediate/short term memory,
- 'disinhibition' to some degree as a result of brain injury,
- right side hemiplegia,
- strong 'emotional memory.'

At the time of the accident our daughter was an intelligent young woman, working in pathology at the Sydney Adventist Hospital, Wahroonga, Sydney.

Previously, whilst still at school, she had worked in a 'casual work' capacity in nursing homes and also for some time after leaving school.

I wish to address this submission in two ways:

1. A personal perspective, as the mother of a young person in a nursing home
2. From a professional point of view.
   My professional background is;
   a) Four Year Trained Nurse, Registration R.N: 0994490
   b) Educationist – BA. DIP.ED DIP.ED.STUD
   c) Psychologist, Registration: P.S. 0002068

1A DAUGHTER'S PERSPECTIVE

(i) MY DAUGHTER'S CURRENT STATUS AS AT JULY, 2004.

- On disability pension.
- Long-term memory quite good.
- Immediate short-term memory gradually returning over the past 2-3 months.
- P.E.G. tube removed.
- Eating pureed food and no. 3 thickened fluid.
- Speech fair to good and intelligible. An effort and especially when tired. Very quick and accurate communication response when using an alphabet chart to spell out words and sentences.
- Bed and wheelchair bound.
- 24 hour care
- Category 1 care.
- Unimpaired comprehension.
- Extremely low self-esteem.
- Inappropriate guilt because she cannot care for herself.
- Some perseveration.
- Occasional disinhibition when stressed and/or fearful.
- Right eyelids scaled, (sutured). Has sight currently in left eye only.

ii) MY DAUGHTER'S PERCEPTION OF HER SITUATION AS A RESIDENT IN THE NURSING HOME.

This is ascertained from her verbal and communication chart to me and from my observations.

- Boredom, unless being visited by friends, family and therapists. She is left alone a great deal. Nursing staff do not have time to pause and chat nor take her for a walk in her wheelchair etc.
- Lack of understanding by nursing staff of a Brain Injured Person and how to care for such a person.
- Lack of basic nursing care by some staff.
- Fears for the future. Because she is in a nursing home, she believes/thinks she is there to die.
- Fear of some of the nursing staff. She has become 'hyper vigilant.' She has very few ways to protect herself. Feels vulnerable, powerless and helpless.
- Dislikes males attending her personal care.
- Fear of choking when being fed incorrectly, eg. when lying down, being fed too quickly. This has happened.
- Fear of not having enough to eat because staff don't have time or forget to give her her meal. This happens quite often when senior staff don't check.

(iii) DISTRESS AND AGITATION

Our daughter becomes distressed and/or agitated when:

- She is forgotten and left alone in room in wheelchair for long periods of time.
- Forgotten and left alone, after dark in her room, in wheelchair with no lights.
- Hungry and no one comes to feed her and her meal is left in her room on a tray. Meals are missed altogether at times.
- Left in a wet and/or messy state in bed or wheelchair for hours without help.
- Wheelchair placed in a position where she cannot see who is coming into her room (her only sanctuary).
- Being patronised, treated like a child. Her comprehension is as good as any who visit her and her carers. As well, her behaviour and responses are adult.
- Staff don't take time to listen to what she is trying to communicate (verbally or with alphabet chart) and don't give her time or don't wait for her responses to their questions.
- When she is left without her glasses (quite often) she cannot see clearly who enters her room or what they are doing.
- No one comes to her aid, especially when she is in an uncomfortable position for long periods of time.
- From her own experience of working in nursing homes, she is aware of treatment by some nursing staff which is inappropriate, rough, unnecessary, discriminating etc.
- Being left in bed all day.
- Being left tired and uncomfortable in her wheelchair for hours and hours.

1B MOTHER'S POINT OF VIEW AND AFFECT ON FAMILY

(Please see Supporting Document 1.)

(i) REHABILITATION COSTS TO FAMILY

As our daughter's accident was non-compensable (one of many persons to slip through the 'Green Slip Cracks") family has had to shoulder rehabilitation costs such as:

- Neuro Physiotherapist
- Speech Therapist
- R.N. Reflexologist
- Specialised equipment such as wheelchair
- Medication
- Hiring of special 'walker,' computer and extras for the disabled.
- Fold-up wheelchair
- Clothing replacement, toiletries etc.
- Purchase of 'Thicken-up' needed by nursing home kitchen staff to make fluids grade 3 consistency.
- Heavier pads (for incontinence) when our daughter goes out from the nursing home for medical appointments, outings etc.
- Disabled Taxi, transport, the difference between fare cost and the Taxi Transport Subsidy.
- Etc.

(ii) STRESS/DISTRESS TO FAMILY

Another very big factor has been extreme distress and stress to the family by inappropriate treatment, behaviour and attitude by nursing home staff towards our daughter, family members, visiting therapists and visitors.

A few examples are as follows:

- Inappropriate and/or exaggerated and/or untrue "Incident Reports." (see Support Document 2).
- Discrimination, victimisation, rough treatment by some staff members
- Medication (unnecessary for our daughter's wellbeing) which held her rehabilitation progress back for more than a year.
- Negative and inappropriate attitudes and in some instances, rudeness to visitors and some therapists by some staff members, particularly between 2002 and 2003.
- Emergency hospitalisation of our daughter when family had to contact our daughters G.P. (General Practitioner) urgently:
  a) She was admitted into hospital for starvation due to staff neglect.

b) Pneumonia. Diagnosed as due to inhaled food from inappropriate feeding methods/ procedure by nursing staff. She was admitted into hospital.

Both of these crises and hospitalisation were due to failure of "Duty of Care" by the nursing home.

- Threatening behaviour from a few senior staff members and board members towards family.

- A case conference organised by family which included Medical Specialists, General Practitioner, Rehabilitation Therapists, Rehabilitation R.N., Social Workers (B.I.U and nursing home), Senior Nursing Home Staff and Family was held at the nursing home mid 2001. It was completely and deliberately sabotaged by Senior Nursing Home staff who ignored the pre-arranged and pre-agreed agenda. They then walked out before specialists, therapists, family etc were able to present their points on the agenda.

  The aim of this conference was to outline how all professionals and family could work together as a team with the nursing home staff so that there would be the best outcomes possible for our daughter, staff, professionals and family.

  The second aim was to discuss as a team how we could progress our daughter's rehabilitation, over time, to the point where she could move into Hostel care.

  The then Director of Nursing was keen at that time to include more young people into her facility as she had had training and personal experience with young acquired brain injured people. From her training and experience she believed that the goal for our daughter to be progressed to hostel care could be achieved in approximately one year.

  Without the cooperation of all senior staff and indeed some strong opposition, this goal was doomed. A few key senior staff were determined to have our daughter removed to another facility as they did not want a young brain injured person as a resident in the nursing home.

- Family's enormous and time consuming efforts to improve the situation were largely ignored. One example was: In the first year of our daughter's residence in the nursing home, I was told and understood that working in a nursing home was highly stressful. I offered, free of charge, to help either individually or in groups, to train staff in relaxation techniques and stress management. Professionally I had not only trained numerous clients but had also trained trainers in relaxation and stress management skills. My offer, given on numerous occasions was never taken up.

(iii) FRUSTRATIONS LEADING TO HIGH STRESS LEVELS

The family, (parents, brother and legal guardians) suffered great stress due to:

- Enormous energy, time, documentation required to protect our daughter.

  A complaint to the Commonwealth Complaints Commission from a person outside of family and staff, about mistreatment of our daughter by some staff members at the nursing home, set in motion a long process resulting in a Determination Review by the Commissioner for Complaints finalised on 15th August, 2002. A copy of this Determination is attached as a supporting document. (See Support Document 3).

  There was no positive change by the nursing home as requested by the Commissioner. It just created an increased negative and somewhat hostile response by the nursing home towards family members and our daughter.

- The Community Outreach Team from the Brain Injury Unit, Royal Ryde Rehabilitation Hospital, gave educational help, advice etc to the Nursing Home staff. All of this effort, expertise given to nursing staff was and has been largely ignored. Change was negligible.

- The next ploy by the Nursing Home was to try and remove family members as legal Enduring Guardians. The Nursing Home was unsuccessful. A copy of "Order Confirming Appointment of Enduring Guardian" from the Guardianship Tribunal is attached as a support document. (See Support Document 4).

  Again, enormous time, effort, documentation added much more stress to our already 'stress-overload' in trying to protect our daughter.

- The total time and increasing stress factor relating to the care of my daughter prevented my continuing in my professional practice. I had a successful and very enjoyable work life in Private Practice as a Psychologist. I hope I can return to it sometime in the future. (See Support Document 5).

  My withdrawal from the workforce also meant limited/less funds available for our daughter's rehabilitation. This creates further stress of a financial kind.

- My physical health has suffered as a result of my daughter's stressful and unnecessarily negative treatment in the nursing home by some staff, particularly by a few senior staff and the subsequent effects on family.

As a consequence of this stress and trauma I have suffered a strong relapse with Myalgic Encephalopathy/ Chronic Fatigue Syndrome. This is the diagnostic term now used by Professor John Dwyer for this devastating and disabling illness. My relapse has also been confirmed by Professor Clifton-Bligh, Royal North Shore Hospital.

This relapse has occurred after 12 years of good health. My cardiologist cannot help me further until as he says, "your stress factor goes."

Add to this, my husband and I are in our late 60's.

- A problem throughout the Health Industry and especially in nursing homes which also impacts on the care of residents and in this case, 'Young People in Nursing Homes', is:
  a) insufficient staff;
  b) turnaround of large numbers of casual agency nursing staff.

  Both (a) and (b) also indirectly as well as directly create further stress to residents' care. (Please see Support Document 6).

  Permanent staff are also adversely affected, leading to elevated stress levels and even to 'burn out.'

  Our daughter's situation and care is further hampered by so many changing staff, (Enrolled Nurses EN's, Assistants in Nursing AIN's and some RN's). Changing and new staff generally, are quite inexperienced in nursing brain injured people. There also seems to be a lack of communication between permanent and casual agency staff as well as between RN's and the 'hands-on' EN's and AIN's. Perhaps time constraints militate against good communication.

  Lack of staff also means many residents' basic care needs are not adequately met.

  Altogether this increases further frustrations and stress levels to our daughter, our family, therapists and medicos.

  At the same time frustration in the nursing fraternity may for some, lead to negative and aggressive attitudes and behaviour toward residents who are much less able to cope and often helpless to deal with this.

2. PROFESSIONAL PERCEPTION

Wearing my combined professional hat (Psychologist, Educator and former R.N.) I shall do my best to remain objective.

(i) ADDITIONAL EMOTIONAL AND PSYCHOLOGICAL TRAUMA TO MY DAUGHTER

- Difficulty with motivation to progress because of environment in which she lives. Other residents are elderly, waiting to die and often suffering from dementia. There are no other residents with whom she can identify.

- Because of the nursing home system and 'system culture' our daughter is in great danger of becoming 'institutionalised.'

- Her senses of smell, vision and hearing are constantly bombarded with the sounds/cries of other residents; the sight of helpless, fragile, twisted bodies of once virile men and women and the smell of incontinence and death and dying.

  She fears, however unrealistically, that she is on the same downward path. There to die.

- Her environment exacerbates her feelings of anxiety and depression in relation to her future.

- Because her comprehension is NOT impaired, but good, she understands her present disabilities, her current helplessness and dependence on others for her basic needs as well as help towards rehabilitation and the goal of independence.

- Having been an independent, unmarried young woman working in a hospital with many friends and an active social life is in strict contrast to her present life.

  It is extremely frustrating and depressing for her. It engenders great emotional and psychological stress. Her long-term memory of life prior to her car accident is largely intact, although there are some areas of confusion. For example, she may remember an event – connect it to the wrong person(s) and place it in an incorrect time frame. Fortunately this is minimal.

- Recently our daughter's immediate and short-term memory has shown positive signs of continuing to improve. This has been over the last 2-3 months and is increasing. Whereas before, she had negligible cognitive memory of new faces, names; in short 'new learning,' Carers' attitudes

and behaviour towards her was not retained. Therefore much negative, harsh, rough and sometimes cruel behaviour, mercifully was not remembered.

However, as with others with post traumatic brain injury, induced amnesia, she did have 'emotional memory.' In brief an example could be: when someone comes to her and she has had a negative emotion with this person previously, such as fear, she will experience this same emotion when she sees this person again, although she will not know why. Her response then to that person will be one of fear.

The fear response would be exacerbated by her feelings of helplessness to protect herself.

Now, although some emotional memory remains, she may remember the name of the individual, be able to describe the person and on occasions can describe the cause of her fear and why she is distressed. Her memory is improving day by day.

The negative side to the return of her short-term memory has led to 'hyper vigilance' and an increased fear and anxiety with a few staff members. Because of shortage of staff together with some staff's lack of understanding, inappropriate people still attend to her on occasions, thus increasing her anxiety and feeling of powerlessness to defend herself.

In her present environment, this has created a dilemma in that she is pleased and positive about what she perceives, quite rightly, that she is able to 'think more clearly,' to remember more recent events and people (new learning) albeit at times with the help of 'memory triggers.' The big dilemma is that the negative aspect means she now recognises and remembers negative attitudes and behaviour from some staff as well as the positives from those who are kind and caring.

She is also much more aware of her environment and circumstances.

Negative staff attitudes which result in such comments to my daughter for example;

- you take up a lot of time
- you are hard work
- I don't have time for you
- A child is easier to look after than you are
- I've only just changed you so you'll have to wait.

have had an immeasurably negative affect on her self-esteem and self-worth. She has had suicidal thoughts and guilt over her disablement, even though there have been many improvements including the real possibility

that she will walk again. Attached is a copy of a recent report by a neurologist. (Please see Support Document 7).

She often says, for example;

"I'm a nuisance"
"I should be dead"
"I'm a worry to people"
"I'm too difficult to look after"
"They don't like me"
"I'm ugly" (which she isn't)
"I'm not worth it"
"I'm causing problems" etc

and she is constantly apologising for needing to be helped with her meals, dressed, changed, transferred between bed and wheelchair etc, etc.

(ii) FRUSTRATION INDUCED TRAUMA

Despite many requests by Guardians/Family and Rehabilitation Specialists (B.I.U) a properly monitored Incontinence Management Plan has not been implemented by the nursing home.

Prior to the accident, our daughter had always been fastidious about personal care.

Regrettably, although Fiona knows when she needs toileting, unless we are there at the time and help her onto a pan or into the toilet, she is left to use incontinence pads. She has no means of attracting attention to be taken to the toilet and realises that staff prefer the easy solution of occasionally checking and changing pads.

As a result she believes she is unclean and smelly most of the time. This has further reduced her already minimal self-esteem, self-worth and self-confidence. She is left frustrated and very embarrassed, especially when she has visitors and therapists with her and to whom she apologises profusely.

This neglect is contributing to her emotional and psychological trauma.

CONCLUSION

I realise this is a lengthy, personal submission but I believe that my and my family's experience of having a loved family member inappropriately placed in a nursing home (because there is no other accommodation for young people) will be useful in giving a first hand insight into the care of Young People in Nursing Homes.

As well, my professional training, experience and skills although relevant and useful have not succeeded in changing the status quo. I hope and pray that this might change so that I can contribute, along with my husband and son who both have different and relevant skills and expertise, to a positive change in the care and welfare of not only my daughter but also the thousands of young people, languishing and forgotten, in nursing homes throughout Australia.

PLEASE take the time to read my poem. It is a very strong support document.

Margaret Fuller