30 July 2004

TO: The Secretary
The Senate Community Affairs
Reference Committee

Suite S1 59
Parliament House
CANBERRA ACT 2600
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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."

Our submission is in three parts.

Part 1 of the submission by Gordon Fuller addresses as an architect the need for an alternative and more appropriate model facility for young brain injured persons.

Part 2 of the submission by Margaret Fuller addresses the physical, psychological and stress related problems resulting from the inappropriate allocation of a young person with A.B.I. in a nursing home.

Part 3 of the submission by Cameron Way (our daughter's brother) will be submitted separately.

Our submissions are written as a result of our personal experience in having a brain injured daughter, now aged 36 'parked' in a nursing home with no appropriate care or rehabilitation procedures.

The attachments to Part 2 of this submission will be forwarded by express post with the hard copy as discussed with Ingrid and Cameron Way on 29.7.04 by telephone (02-6277 3515).

Sincerely,

G. Gordon Fuller
M. Arch. F.R.A.I.A

Margaret Way-Fuller
BA.DIP.ED. DIP.ED.STUD. R.N. R.T.C.

TO: The Secretary
The Senate Community Affairs
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PART 1: SUBMISSION BY:

G. Gordon Fuller M. Arch. F.R.A.I.A. J.P

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 has addressed the problem of a younger person with traumatic brain injury resident in a nursing home.

The submission is written from personal experience as my wife and I have a 36 year old brain injured daughter who has been 'living' in a nursing home for 3½ years.

Sections of this submission include

A. Background
Problems associated with lack of appropriate care are addressed together with family stress.

B. Definitions used.

C. Inappropriate Placement Criteria
This section addresses the custodial care of young A.B.I. residents in a nursing home and the inadequate funding allocation to provide appropriate care. There is a need for an environment which is positive with real potential outcomes, for these people.

D. Restrictions to Change
Identification of responsibility is investigated together with the need for governments (Federal, State and Local) to work together to achieve, as a matter of urgency, a viable outcome.

E. Challenges for a Future Model
Recognition is made of existing projects which are catering for specialised care of younger persons in an appropriate environment. Questions are addressed regarding the possibility of change.

F. The Future – A New Model
Based on my investigations and experience I suggest the concept of a 'Well House' with small accommodation pods where 5 disabled persons can bond together with one able bodied person, creating a strong synergy in the group and providing much needed carer/volunteer support staff.

G. Conclusion
We cannot be complacent any longer – we must all look at a much wider national approach to this serious problem.

A. BACKGROUND

I am an architect with 46 years experience having spent the last 18 years involved in the design, documentation and administration of nursing homes, hostels and specialised dementia units. I have also attended and addressed aged care conferences and been involved in research associated with the modification of an existing redundant aged care facility for re-use as a rehabilitation facility for younger people with an Acquired Brain Injury. I have been on the Board of an Aged Care Provider, am currently Consultant Architect to Sunshine Homes (Downs Syndrome) and the Motor Neurone Disease Association. I am currently a member of the U.P.A. of N.S.W. Aged Care Association Sydney North Committee.

My wife and I also have a daughter, injured in a car accident in December 1999 (non-compensable), who has been inappropriately accommodated in a nursing home over the past 3½ years.

As the nursing home is not capable of providing pro-active rehabilitation we have had to prepare a case management plan involving the appointment of specialists such as a Neuro-physiotherapist, a speech therapist, outreach services from the brain injury unit of the Royal Rehabilitation Centre (Ryde) and a psychiatrist specialising in disinhibition, together with associated behaviour patterns resulting from her traumatic brain injury.

Note: I appreciate that most nursing homes are not adequately funded (even Category 1 level) to care for persons with A.B.I. A recent submission by the Victorian Young People in Nursing Homes Consortium to the Commonwealth Aged Care Pricing Review indicated that a younger person with 24/7 care requirements in a nursing home only generates a Government contribution of $44,000 whereas a more realistic figure to provide proper rehabilitation, well trained staff, therapy and appropriate day activity programs would range between $56,500 and $73,000!

Placement in an aged care environment does not therefore result in Government savings as adequate needs are not being met. This results in these younger people being ‘parked’ in an environment resulting in a poor life-style that is anathema to those sought by the disability and aged care standards.

As a family this has caused us to become assertive and proactive guardians to *try* and obtain a positive outcome and future for our daughter, in an environment that is trained only in palliative care within ‘God’s waiting room.’

This has caused enormous stress and unbelievable time in defending our daughter’s right to adequate and duty of care in an aged care facility where there is an inadequacy of service and an inappropriate setting. The presence of younger people in nursing homes (some 6000 currently Australia wide) challenges providers and places an unbelievable pressure on the system.

Thousands of young adults are eking out a miserable existence in nursing homes for the elderly because the Government has been blind to their real needs for over 2 decades. The suffering and loss these people and their families experience on a daily basis is exacerbated by the inability of State and Federal governments to repair gaps in the social safety net.

The situation is getting worse as the population ages, creating higher care bed demands. Many elderly folk who have been home carers and who can no longer cope with such demanding work, will need to place their disabled child or relative into the government care system, further increasing demand.

This submission therefore tries to address an alternative residential rehabilitative option for young people with A.B.I. and other major disabilities in a more appropriate and enjoyable environment.

B. DEFINITIONS USED

Acquired Brain Injury (A.B.I.) -	An injury to the brain resulting in deterioration in cognitive, physical, emotional or independent functioning.
Traumatic Brain Injury (T.B.I.) -	An injury caused by an external event such as a blow to the head, fall or impact from a vehicle accident resulting in a similar deterioration to A.B.I.
Case Management -	Coordination and monitoring of services and resources together with personal understanding related to a person's specific needs and the promotion of rehabilitation procedures to promote long term independence.
Disinhibition -	The loss of restraint over a thought or urge.
Rehabilitation -	Any process (physical, psychological or emotional) which enables and improvement and long term restoration of optimal functioning after T.B.I.
Slow-to Recover Programs	Catering for the needs of people continuing with rehabilitation after A.B.I. This will vary from 24/7 support for personal care and daily living to verbal prompting and activity supervision. Care would be for a period of 3 to 5 years and would cover treatment for the reduction of disinhibition, challenging behaviour and poor anger control in order to reduce conflict.
Living Skills Programs	Catering for persons with A.B.I. who may have lost normal living skills due to an extended stay in an in-appropriate environment such as a nursing home. Such a program could also satisfy a refresher development for those capable of moving into more independent living arrangements. Care could be for a period of 6 to 18 months.
High Care Support Services -	Catering for persons whose rehabilitation goals have plateaued and still required high levels (24/7) physical care. Such persons would preferably be located in purpose built 'cottage style' accommodation as an adjunct to an existing aged and disability care provider.

C. INAPPROPRIATE PLACEMENT CRITERIA

- My comments and recommendations focus particularly with people aged 50 and under with A.B.I. or similar disabilities such as M.S., ME-CFS, early stroke victims and M.N.D. generally resident in nursing homes on a long term basis.

- I argue that younger people with any of the above disabilities should not be assessed by 'A.C.A.T.' teams for admission to residential aged care facilities and that those currently 'custodially' located in nursing homes should be relocated to a more appropriate rehabilitative environment with specialised support services.

- There is an erroneous belief that aged care facilities are seen as having 'high quality' medical/nursing care (nothing could be, in my opinion, further from the truth).

- In June 2002 the Commonwealth Department of Aged Care noted that 420 persons under 50 years of age were occupying nursing home beds. In 2004 this number has risen to over 600. Most of these young residents are classified high care (Category 1).

- Only 1% of community aged care packages allocated were under 50 years in 2000. This situation has hardly changed in 2004.

- The current cost to accommodate a younger A.B.I. or similar disabled person in a nursing home is of the order of $325.00/day. The maximum Category 1 funding provided to a nursing home is in the order of $125.00/day (including disabled pensioner supplement and resident contributions).

  This means a provider has to either skimp on an A.B.I. resident's high care level or 'borrow' man-hours from lower category residents. This is a policy for disaster as providers have to reduce staff/resident ratio to a minimum.

- In a residential aged care environment the focus is on maintenance and slowing down further deterioration in the body's aging process. This is quite different to a disability service ethos, which should foster and develop the younger person's ability and potential. Many younger persons in nursing homes will therefore over time lose their previously individual skills and abilities.

- The placement of disabled younger people in an aged care facility where death is an accepted occurrence, may contribute to the perception that they are sick and 'awaiting death,' influencing their opinion of the care they receive rather than the care they *need*.

For the above reasons research into planning and design is essential to ensure their environment is positive with real potential outcomes for each individual, their guardians, family and friends, especially to maintain peer support networks.

A specialised facility must be carefully resourced, with effective service delivery and staff training. Funding packages should, in my opinion, stay with the individual rather than the provider so that on-going financial support is guaranteed throughout the whole rehabilitation program. Such a design must identify and highlight on-going opportunities for new learning and development yet be of adaptable design to allow planning changes, especially if the project is of an experimental or 'pilot' nature.

D. RESTRICTIONS TO CHANGE

Any approach to specialised care for younger persons requiring full rehabilitation must involve Commonwealth, State (including opposition parties), local government agencies and independent authorities. In NSW this specifically relates to:

- N.S.W. Department of Aging, Disability and Home Care
- N.S.W. Health
- N.S.W. Department of Housing
- N.S.W. Department of Infrastructure Planning and Natural Resources
- The Motor Transport Authority
- Local Government Development Control Plans
- Vehicle insurance providers.

Unfortunately to date there appears to have been unwillingness for both the Commonwealth and States to engage in and take responsibility for younger disabled persons inappropriately placed. It is also obvious that no acceptable policy has been addressed to date to overcome this vacuum, especially as the placement of younger people in residential aged care facilities is inconsistent with the NSW Disability Services Act (1993).

People with disabilities in NSW are covered by two pieces of legislation.

1. The NSW Disability Services Act (1993).
   This act provides for the funding and accommodation support by the State Government underpinned by service provisions that address the rights of disabled persons.

2. The Commonwealth Aged Care Act
   This act has no reference to the needs, rights and interests of people with a disability. This act covers the accreditation of approved providers (the N.S.W. Nursing Homes Act governs the licensing and operation of residential aged care facilities in NSW).

It is clear that the main issue is therefore a lack of sufficient government resources to address this problem of dynamic proportion. This problem appears to have been bypassed because people with sufficient compensation payouts can purchase appropriate support services privately and do not move into residential care facilities.

This means that non-compensable young persons with a disability fall through a crack in the system and are given no alternative opportunity.

The availability of services is therefore based on purchasing power, proving that with sufficient resources alternative solutions can be found. It should not be forgotten that the admission of a young disabled person into an aged care facility immediately lets governments ‘off the hook’ as the crisis in special care and support evaporates! This then reduces the priority rating as the younger person is in a ‘home’ and their real needs are no longer an embarrassment.

Before addressing a new model for the care of younger disabled persons it is therefore necessary for all authorities to resolve and simplify responsibilities.

The objectives of the NSW Disabilities Act relating to community living do not apply to residential aged care facilities therefore younger people with A.B.I. or similar disabilities are not afforded the protection this Act provides.

For Example:

- There is no incentive to increase independence and integration.
- There in no requirement for individual planning aside from medical treatment. This can even be misused with both medical and physical restraint to make caring easier for staff!
- There is little likelihood that a younger person with a disability will have access to age appropriate facilities or activities.
- Expertise in the monitoring and review of their care circumstances is limited or non-existent.
- Whilst young persons in residential care facilities have access to the aged care complaints resolution scheme, their complaints can only be dealt with within the context of the service type with no reference to the D.S.A or its service standards. This requires guardians of younger residents to be continuously vigilant.

A.B.I. or any disability of a family member is a 'keystone' event in the lives of the family and friends.

Timely intervention immediately after trauma, medical technology, adaptable and appropriate rehabilitation, psychological encouragement and pro-active family and friends is all well and good **but if** aftercare and follow-up treatment are wanting (as in a nursing home) this is all an incredible waste of public money and professional expertise.

It is the rehabilitation of the whole body (a holistic approach) that is important – diet, muscle tone, incontinence management, balance, memory triggers and many more. Barriers to these elements of recovery are nearly always due to lack of specialised training, ignorance and lack of a pro-active will to encourage the individual.

Human Rights & Equal Opportunity Commission outcomes should create an enabling environment where people with a disability have the opportunity to achieve the best of their potential. There is a need for appropriate support to 'enable' the disabled to integrate back into the community.

E. CHALLENGES FOR A FUTURE MODEL

Western Australia and Victoria have developed alternative models for the care of younger persons with A.B.I. or similar disability. I have visited experimental projects developed by the Brightwater group in W.A. These facilities range from the construction of specialised living skills care homes within the community (up to 6 residents) with full wheelchair access and 24 hour staffing, to high care facilities (24 bed) in 3 interconnected homes catering for full rehabilitation and medical care. This includes incontinence management, peg feeding, physiotherapy techniques and an appropriate, relaxing, fun-filled activity program.

The Head Injury Council of Australia in August 2001 supported the concept of specialised care for young people with A.B.I. stating in a media release;

> "Aged care institutions are not designed for young people who require age appropriate supportive accommodation, rehabilitation and access to inclusive community programs. Their rights and opportunities should not be compromised by financial rationalisation but should be governed by equity and the Australian philosophy of a **fair go** for all people regardless of age or disability."

It is true, the article goes on to say, that;

> "This situation is still occurring in Australia in the 21st Century is an indictment of Australia's health care system and its governments. … H.I.C.O.A. urges the Federal Government to take a leadership role and to work with State governments to resolve this issue. … Mutual obligation applies to governments as well as citizens and that positive change can be brought about by Australians working together."

It is therefore welcome that such a senate enquiry into aged care has included concerns relating to the appropriateness of young disabled persons being allocated into an aged care environment.

Innovative programs have and are being developed here and overseas to address a more appropriate care model. These need to be evaluated by an expert team made up of specialists in both Government and the private sector.

The following is a brief list of major matters and questions to be addressed, some taken from a discussion paper dated September 2002 supported by People with Disabilities (PWD), M.S. Society and the Brain Injury Association of NSW Inc.

- How can younger people *currently* living in aged care facilities be moved into more appropriate accommodation and how can this be prioritised?

- What happens if government policy insists that A.C.A.T. no longer access people with disability to an aged care facility?

- What strategies need to be implemented when a policy of no new admissions is introduced under the N.S.W. Aged Care Act?

- What is the best practice currently available to younger disabled people with intensive needs already in the community?

- How do we build and finance such projects? Should insurance companies re-assess compensation payouts to ensure capital funding is available for research and pilot projects?

- How can not-for-profit service providers build specialised facilities confident that adequate funding will be provided long term?

- How can best practice be replicated consistently across the state?

- What pilot projects have been fully evaluated and how have they been funded?

- What will happen to the dollars currently spent on younger disabled persons living in aged care facilities?

- What level of government is to become responsible?

- How can pathways be developed for younger disabled persons **excluding residential aged care facilities as an option?**

THE FUTURE – A NEW MODEL

"Through intelligent and innovative use of design and technology we can make sure the current impasse does not defeat us."

These words are from an architectural colleague of mine, Peter Phippen OBE Architect. In his Abbyfield address in 2000 he refers to going into a 'Well House' instead of a nursing home. Its primary function is to get people well after trauma and injury such as A.B.I.

This is what governments and service providers must face up to – a better living and caring environment than that which currently exists so that the 10,000 or so young people with A.B.I. or similar disability will, in 2007, have a more appropriate alternative.

I see such an alternative as having living pods, or group homes – possibly each with 6 residents, living in a small four pod clusters under the control of an R.N. experienced in A.B.I. care together with at least four selected carers (say 3 shifts) to provide 24/7 on site care. These carers would provide nursing care/activity interests and coordinate rehabilitation programs. A part-time cook would attend each day for the main meal and prepare a light evening meal for distribution by the carers.

Specialised equipment (lifters, commodes, wheelchairs, weighing chairs, re-chargers, elevated spa bath, water chairs and low-level adjustable beds) are essentials and adequate space and storage is required.

Cameron, my daughter's brother, has suggested that a mix of 'able' as well as disabled persons would have an enormous social benefit. Low income (students) fit persons could assist and support the full time staff, creating a strong synergy within the group, encouraging and stimulating the disabled resident to move forward and achieve new goals, the able bodied, in the process, achieving greater self esteem and a community spirit. Such 'students' or others would pay a reasonable rent for 'board and lodging,' so helping offset running costs.

The method of capital funding, site availability and recurrent costs, is of vital importance and considerable research will be required to determine a realistic and viable model. Traditional forms of funding may not be appropriate and some lateral thinking is essential.

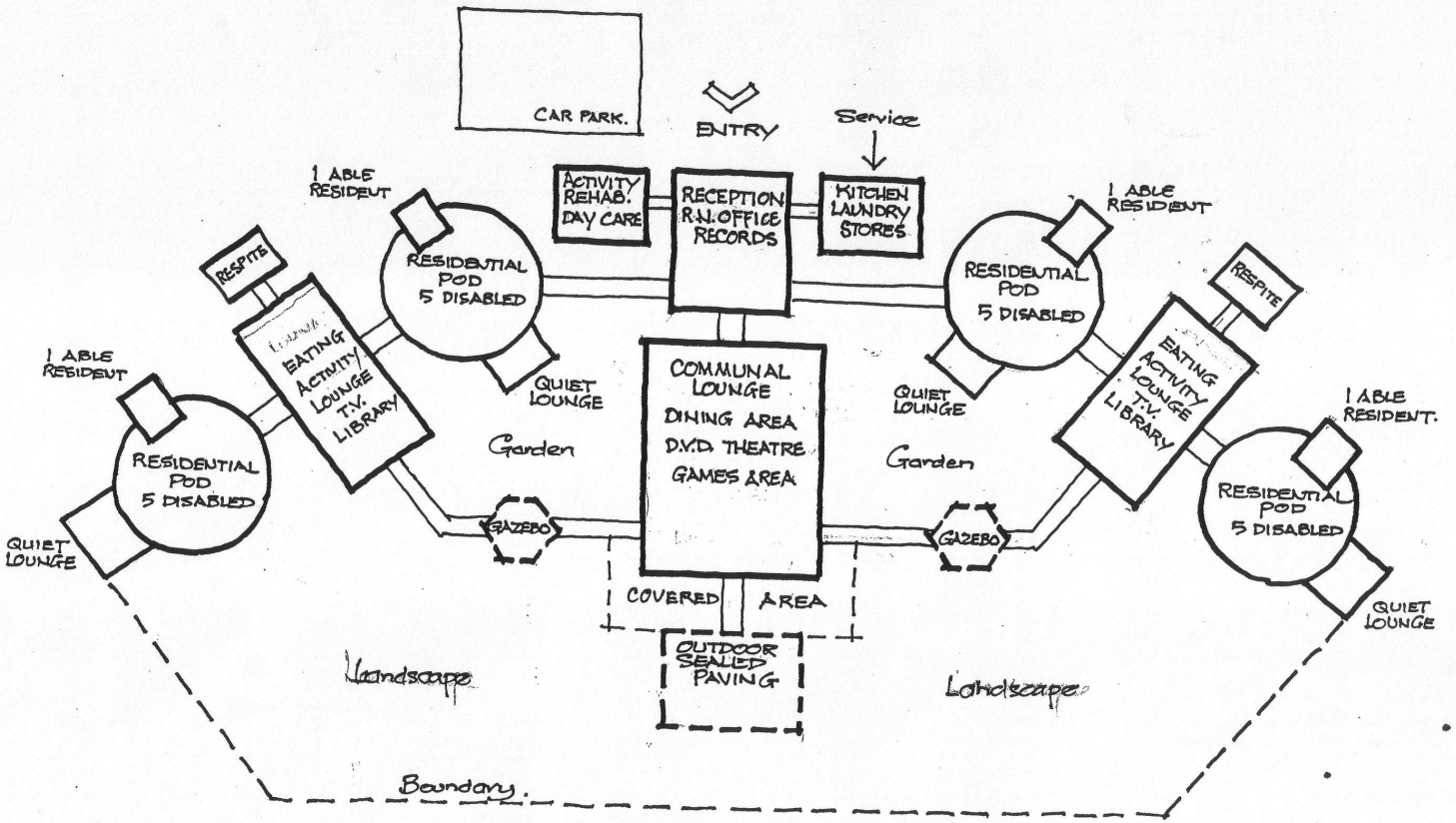
Universal design is very important in looking at such a model. Exclusivity of design becomes a problem if accommodation only addresses the needs of a select group. Whilst wheel-chair (electric) accessibility is of paramount importance, flexibility is essential, respecting the needs of the able bodied carers, guardians, family and friends.

Design matters which should be addressed are:

- A home-like environment, well away from an institutional character.

- Recognition that the kitchen and adjacent activity area are common gathering points.
- An open plan design for easy observation.
- A stimulating environment with good interaction between indoor and outdoor (covered and uncovered) areas.
- Personalisation of furnishings and objects in residents' rooms.
- A youthful environment with age appropriate music, activities, artwork, videos, DVD's and furniture.
- Quiet and private small lounge areas away from bedrooms so family and friends can bond with the resident.
- An open garden area with good paving and summer shade.
- Large bedrooms with en-suite (specially adapted for showering a disabled person).
- Variations in style and décor – room to room with an overall warm tone throughout.
- Respite facilities should be provided as it is often difficult for young people with A.B.I. to access such services. I am concerned that respite services are not readily available for families who are most often in need of a break from intensive caring.
- Wide corridors (wheelchair passable) and wide (900mm) doorways.
- Single room accommodation.
- Identify areas in private room for sleeping and living. Provide tea making facilities in rooms (generally accessed by family and friends).
- Outdoor covered space to each room – secure.
- Staff sleep-over facility/active night shift.
- 1 bedroom per 'pod' for an able bodied person.
- Peer appropriate facilities for meaningful activities.
- Large shower cubicles giving carer access.
- Possibly a family accommodation unit.
- Security after-hours.

The following spatial diagram shows the 'pod' concept and the linkage between each area and how each group has the potential to interact with the other, providing a sense of community spirit and social mix.



CONCEPT FOR A 'WELL HOUSE'

ACCOMODATING YOUNG PEOPLE WITH A.B.I. M.N.D. - M.S. OR OTHER SIMILAR DISABILITY

G. Gordon Fuller 2004.

G. CONCLUSION

What I find of great concern is the number of reports, 'papers,' conferences and discussions, media releases and public outcry regarding the inappropriate 'custodial care' of young people in residential aged care facilities. The same concerns have been raised in the last 10 years.

We (that is Australia) can no longer afford to be complacent. Action to provide appropriate facilities must be addressed now to avoid a national disaster by 2008.

For me it is imperative that both Federal and State governments move from the small scale observation of localised innovative projects and now look at a much wider national approach.

G. Gordon Fuller

H. REFERENCES USED IN THIS SUBMISSION

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3. Abbeyfield Lecture (2000) – 'Building for Longevity' by Phippen OBE DipArch RIBA.

4. Notes from a NSW Premier's Forum (2003).

5. "Universal Design," Extracts from the 6th Global Conference in Perth WA – Maturity Matters (October 2002).

6. Young People in Nursing Homes – National Alliance, Priority Action Plan Paper (2002).

7. Brain Injury Association of NSW Inc.

8. Personal notes relating to my daughter's experience as a 33 year old from 2000 to 2004 in a nursing home.

9. Head Injury Council of Australia (HICOA), Media Release (August 2001).

10. Discussion Paper (2002), "Younger People with a Disability out of Nursing Homes" by a Consortium of Disability Associations including B.I.A. of NSW Inc, M.S. Society, People with Disabilities NCOSS etc.

11. Submission on the Impacts and Costs Associated with Housing People Under 65 in Residential Aged Care, (2004) by Victorian Y.P.I.N.H. Alliance to Commonwealth Dept. of Health and Ageing.