Through collaborative activities achieving a new quality of life for persons with acquired brain injury

VBIRA

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The Secretary,
Senate Community Affairs References Committee,
Suite S1 59
Parliament House,
CANBERRA A.C.T. 2600

INQUIRY INTO AGED CARE

This brief submission by the Victorian Brain Injury Recovery Association Inc. (VBIRA) is restricted in its focus to those residents with Acquired Brain Injury with special care needs.

It is made in response to the Inquiry Reference

(c) the appropriateness of young people with disabilities being accommodated in residential care facilities **and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;**

and

if permitted by the Committee: under the Terms of Reference matters (d) (e) (a) & (b) which are **restricted** to the **elderly/aged**, as a high percentage of these residents have severe Acquired Brain Injury.

The submission reflects views of VBIRA Members - all are health professionals - who manage and treat brain injury in all its manifestations and presentations, and in undertaking this work are regularly involved with patients/clients who are accommodated in residential aged care facilities. These health workers formed VBIRA primarily as an **education forum** to enhance their skills in **the rehabilitation** of persons with severe Acquired Brain Injury.

VBIRA asks the Senate Committee to accept this submission in the knowledge that the Association wishes to co-operate with moves by governments to improve the health of persons with severe Acquired Brain Injury wherever they may be accommodated. Members are ready to meet with the Committee to expand on matters raised in this submission, and discuss possible actions - both major and minor - which the Committee feels could be initiated in both the short term and over years to come.

Yours faithfully,

Tom Worsnop
Secretary.

VBIRA submission:

Background:

Underlying this submission are two contentions:

(a) if given timely and adequate rehabilitation, a significant number of residents with severe ABI now living in aged care facilities could be returned to home/community living, thus freeing up beds now denied long-term to frail aged persons who have been assessed as needing nursing home care; and
(b) current rules/regulations/structures and resourcing of publicly funded aged care facilities **inhibit** and often **exclude** rehabilitation programs which could give "new life" to many with ABI, and enable them to find a quality of living which they are presently denied.

In this context we are talking about thousands of people - from children to the the aged - and the numbers are climbing.

March 2004 statistics from the Department of Health and Ageing, of the Australian residential aged care facilities population, reveal a total of 6,261 persons aged under 65 years. the largest category - 30% - having Acquired Brain Injury (ABI). To this figure must be added those aged over 65 with ABI. The Australian Institute of Health and Welfare breakdown of permanent residents just in **aged care nursing homes**, show 85% are aged over 75. and a high percentage of residents over 75 have Acquired Brain Injury. It is therefore not irresponsible to speak of several thousand residents with ABI living today in aged care facilities - a significant number with an increasing trend, and having a common need for **long-term high level care**, clogging-up nursing homes and thus denying frail old Australians care beds they urgently need.

Residents with severe ABI:

VBIRA is deliberately limiting this submission to persons with **severe** or Diffuse Acquired Brain Injury, by definition excluding genetic or degenerative neurological diseases.

Acquired or Diffuse Brain Injury is the result of a wide range of causes, the more common being: cortical stroke - especially haemorrage; major sudden impact trauma - falls, accidents, high velocity penetration (eg gun shot); hypoxic injury - drug overdose, failed suicide...; subarachnoid haemorrhage; medical accidents; and encephalitis. Diffuse ABI is medically complex, and presents major care and rehabilitation challenges to health professionals.

Features of severe ABI include: impairments which are usually not predictable on the basis of medical scanning; a variety of motor, sensory, brain stem, cerebellar and cognitive impairments; and rehabilitation which is usually very complicated. In the initial acute hospital severe ABI involves managing loss of consciousness (which may be brief or quite prolonged), & post traumatic amnesia (which may well extend past the time a patient is in the hospital setting - weeks, months....).

The long-term impairments resulting from ABI can be described:-
Non-physical - cognitive, behavioural, communcation, social:
Physical problems can include - paralysis, spasticity, pressure areas, scoliosis, contractures, swallowing, bruxism, ptysalism, epilepsy - generalised and/or focal, tremors, heterotopic ossification, vision & other sensory impairments.
This listing is not exhaustive, but demonstrates the need for a high level of skill training for any in the health team charged with the care of persons with ABI, immediate and long-term.

Advances in acute medical care over recent decades have resulted in a significant change in the ICU "survival rate" of Acquired Brain Injured patients. In years not that long past, severely acquired brain injured were not generally expected to "survive", but now the question is frequently "survived for what?" This is the dilemma which is suddenly, and without warning, faced by the distraught partners/familes/friends, as the public hospitals tell them they cannot provide patients who are uninsured or who are noncompensible, long-term care for their loved ones.

Accommodation options for ABI:

The wives/husbands, families, friends... are given the hospital's position as being beyond challenge. VBIRA members frequently report how families are virtually faced with solving this problem with minimum asistance by the hospitals. So often because of the high level of care needed the choice given is "a nursing home if you can find a spare bed" or "home for you to provide the care with maybe some community/local government/charity support".

For patients with resources and family/friend support, there are options in the private hospital and private medical systems - even if there may be some time delays in accessing these. When these families/friends networks are faced with this situation, "all stops are pulled out, contacts made and influences used" to ensure appropriate immediate care is provded, and rehabilitation commenced to maximise potential for health improvement, and most importantly minimise the adverse medical results of minimal medical care and rehabilitation.

For the growing numbers who are uninsured or noncompensible and who haven't the financial and/or physical abilities for alternate options, with the "not-too-subtle encouragement" of the "system" the "nursing home" option is reluctantly forced upon them. This is the "target group" which VBIRA highlights to the Committee as being presently denied fair and proper treatment, and whose voice to date is being ignored by Governments and health authorities.

Nursing homes are inappropriate for persons with severe ABI:

By their designation, design, staffing & financing, present day nursing homes which are reliant upon Government funding, are not a satisfactory accommodation option for severe ABI residents.

The typical Victorian nursing home resident profile is: female, advanced in years - closer to 80 than 70, requiring end of life care and with a life expectancy of weeks/months not years. This is in conrast to the profile of the severe ABI person needing accommodation who is more than likely to be a male aged many years below other residents, who requires specialised nursing attention and care which is not funded, often special equipment which is not available, and very necessary - the availability of accessable rehabilitation programs, with this level of care and attention being required for years, maybe many years.

This submission has several times used the term "rehabilitation" which is the antithesis of the end-of-life/terminal context of general nursing homes to which many severe ABI patients are sent to by our acute hospitals. While in some countries rehabilitation is becoming expected for all with ABI, in Australia it is only widely available to the affluent or 3rd party funded residents. When the issue is canvassed, it is generally averted as falling between the areas of State and Federal governments, too big a problem, or too difficult/costly.

> *"Management of neurological impairment and in particular severe brain injury and impairment is the most difficult area of rehabilitaion. It presents very complex clincal problems in areas of physical management, cognitive management, and behavioural management. Perhaps even more difficult are the problms of social management of not only the patient, but often more importantly the patient's family and carers."* A/Professor Barry Rawicki addressng ABI professionals.
> *"Management of severe brain injury is not high profile, it is not sexy..... These patients do not attract government attention or funding anywhere like in proportion to their numbers or the social and personal impact that results."*

Importantly what must be emphasised in this submission is how the current rules and regulations controlling government funding of nursing homes **prevent** residents from receiving rehabilitaion and assistance available to severe ABI home/community residents. This surely is not the intention of these rules and regulations, but they add to the complexities for those trying to introduce even limited rehabilitation to some severe ABI **now** in nursing homes.

A present simple example:

> Male - married with several children, heart attack mid-40's, severe ABI resuscitated in major Melbourne hospital, given the option of home in a rural setting or a city nursing home discharged to home with no rehabilitation follow-up. He was lovingly cared for for some years, but as his physical impairments became too much for the family (no local skilled therapists available to prevent this), he was admitted into a nursing home. His children tried. but eventually couldn't face seeing him always in the company/environment of the aged care nursing home, and the family break-up seemed inevitable. In time his condition improved to the point where now the family feel they could cope with Dad over week-ends, in an attempt to hold the family together.

This plan has doctor's endorsement, but cannot be effected. Why? Because on admission to the nursing home, his wheel-chair, (which the family specially modified years ago to his specific needs), was **repossessed** by the Government Department under the rules of the Federal funded PADP Program!!!!

A more widespread practical example:

Nursing homes have over recent years become far more careful re Occupational Health & Safety, along with ever increasing insurance premiums. A common situation now is a **"no lifting"** policy applying to all staff - particularly nurses & PCA's.

Because of the ABI cognitive limitations (e.g. inability to understand or follow simple suggestions re movement), often combined with contractures, at least two staff will often be required to move residents, not just transfers but for daily showering and toileting etc.. This requirement poses **two** demands on normal nursing home staff - first the need to have staff specially trained about lifting and positioning those with severe ABI, and then to often have to require 2 staff to attend ABI residents when rosters schedule solo attendance.

This second example highlights the problems of staff training and workforce shortage - which relates to Reference Term (a):

As previously mentioned, severe ABI management requires special skills, not just re neurology and medical physical care, but also for nursing and therapy workers. Physical positioning of a resident relates also to pain reduction & avoiding complications during feeding where there are swallowing difficulties; lifting is another area which is complicated by the severe ABI resident. The whole "knowledge area" re ABI needs to be at least partly learnt by all staff involved in severe ABI care & the 2004 Budget **does not have adequate proposals** to meet these extra staff work-force needs and extra staff training. This is a very sensitive issue in the not-for-profit nursing home sector where nursing staff wages **are already 15% lower than in the public and private** systems, so requiring extra training on top of extra staff to adequately provide proper care levels presents funding problems.

Nursing homes disrupted by severe ABI residents:

Behavioural problems, (e.g. shouting, inhibition, wandering, "hitting out" arm and leg movements), are commonly cited by nursing homes as "disruptive" and "unaccepable" behaviours which adversely affect other residents. Residents object to how extra staff attention has to be given to "controlling" residents with severe ABI which results in less attention & assistnce to others.

No government funding is available to soundproof and damageproof rooms to be occupied by residents with severe ABI, making nursing home managements unwilling to accept residents with severe ABI.

H&CC Programs - Terms of Reference (d) - must also be raised:

Health & Community Care programs can be accessed by those with ABI who are living in the community. But once in a government part-funded nursing home this is not permitted. While possibly only limited numbers with severe ABI may be so precluded, this does not justify such a prohibition - particularly when other residents in the nursing homes, that is the elderly, have access to HACC programs.

Where to from here?

VBIRA realises that persons with severe Acquired Brain Injury have been admitted to government supported nursing homes for many years, not because they fit the requirements of being frail and aged, but under emergency or compassion provisions of the Federal & State Agreements where the State has no other available option.

The medical treatment & management of the severely brain injured has progressed over recent years. Mild head injury management is largely coped with in the general community, and is available to all concerned regardless of their financial circumstances.

Those with Severe Brain Injury now deserve the option of leading a life - not necessarily as before their significant trauma - but a "new life" made possible by rehabilitation programs. Published research of programs world-wide, and limited Australian programs have clearly demonstrated how with timely and adequate designed rehabilitation programs, large numbers who experienced severe Acquired Brain Injury have been rehabilitated so that they now can enjoy a quality of life previously not available to them.

VBIRA accepts that the whole issue of appropriate accommodation for uninsured/noncompensible persons with severe ABI is a major deficiency (to use kind terminology) in the health system, which needs urgent attention, and which we do not expect to be suddenly remedied. However the process of at least starting to seriously examine how actions can be taken to induce change must be begun.

This is the challenge VBIRA puts to this Senate Committee. It is not beyond your remit to acknowledge this medically indefensible blot in the country's health system, and to recommend that the Australian Parliament initiate practical Federal/State actions without delay to fully investigate appropriate, affordable and accessable rehabilitation for citizens with severe ABI.
