SUBMISSION FROM THE NATIONAL BRAIN INJURY FOUNDATION

TO

THE AUSTRALIAN SENATE COMMUNITY AFFAIRS

REFERERENCES COMMITTEE

INQUIRY INTO AGED CARE

1. This submission will be exclusively concerned with the appropriateness of young people with disabilities being accommodated in residential aged care facilities.

2. More than a decade of research and comprehensive data collation including a National Summit in 2002 and a National Conference in 2003 has placed beyond question the severity and the magnitude of the problem of younger Australians who are confined within nursing homes. The National Brain Injury Foundation (NBIF) bases this brief submission on a presumption that all members of the References Committee are convinced of the extent of the problem and will have gained an insight into its social impact from many of the excellent submissions they have received. It follows that the only outcome of the Inquiry which could justify the referral will be some realistic proposals for solutions.

3. The direct experience of the NBIF that is relevant to the Inquiry concerns that subpopulation of younger people who have been placed in nursing homes as an alternative to attempting to rehabilitate them after acquired brain injury. That experience has been gained over the course of 15 years during which the Foundation has represented the interests of many people living with acquired brain injury, and their families, in Eastern Australia.

4. Estimates of the number of younger people in Australian nursing homes with acquired brain injury (ABI) range between one quarter and one third of the overall population of 6000. The first point to be taken into account in attempting to implement solutions to the national scandal that these 6000 individuals constitute is that their life expectation, the level and nature of their dependency, their potential for improvement with rehabilitation and, consequently, the measures that should be implemented to assist them will depend upon the medical category within which they fall. One size, most assuredly, will not fit all. The second point is like the first. The best solutions, even within the subpopulation of younger people with acquired brain injury, will vary with both medical and non-medical features of the individual person. Medical factors will include the severity of disability, the time elapsed since injury occurred and the extent of any associated non-neurological injury. Non-medical factors will include geographic

location, family structure and financial circumstances and preceding educational and occupational status of the affected individual.

5. The message from the preceding point is clear. Measures to assist each younger person with ABI in a nursing home must be individually targeted. This point could be illustrated in numerous ways: one example will suffice. The transfer of a person with ABI from a nursing home to a group living situation in which a range of rehabilitation services are available on a continuous basis may be ideal if that person's family resides in a city. However, if the livelihood of the immediate family centres on a farm 6 hours from the city, the identical solution becomes far from ideal.

6. The problem of younger people with ABI in nursing homes can be seen, on closer inspection, to be two problems and, in accord with the point made above, two solutions will be required. One problem, which is readily apparent, is that of an obscenely large number of people already ensconced in a nursing home. The second problem, less apparent but hardly requiring an Einstein to appreciate it, is that of the continuing, utterly inappropriate, entry of additional younger people with newly acquired brain injury into residential aged care accommodation. NBIF submits that two distinct approaches are required if the recommendations of the References Committee are to do any more than gather dust alongside many predecessors.

7. With reference to the second problem, namely the continuing entry of younger persons into nursing homes the administrative solution to this already lies within the capacity of COAG and this submission does no more than support requests already made from a number of quarters for an urgent referral to COAG of the increasingly dysfunctional dichotomy inherent in the Commonwealth/State and Territory split in provision of services in health, disability and aged care. No integrated administrative solution appropriate for the first problem, namely assisting younger people now in aged care facilities, currently exists. The remainder of this submission outlines a model for such a solution.

8. Notwithstanding the obstacle of lack of an "off the shelf" process to solve the problem, one positive aspect should be kept in mind. This is that it can be viewed as a "one off" challenge. (This assumes that COAG reaches an agreed position which curtails future influx of younger persons with disabilities into aged care facilities. This assumption is buttressed by awareness that nursing homes are increasingly refusing to accept this category of residents and that, in the absence of joint Commonwealth/State and Territory action, the Australian aged care system will inevitably break down).

9. Release of younger people now in nursing homes should be considered as a rescue operation and the most appropriate analogy of this is the national response to Cyclone Tracy in 1974. On that occasion, the need for an adequately resourced task force with a clear goal and a limited lifespan was readily recognized. In 2005, another well defined Australian population remains in urgent need of nationally coordinated assistance. Of course there are differences between the two situations. Tracy was an acute event which attracted enormous media attention whereas the present 6000 have entered aged

care facilities surreptitiously over a number of years. Tracy's victims were all in a single location rather than in facilities spread over the continent from Cairns to Perth. Tracy was outside human control whereas the 6000 owe their predicament primarily to a lack of bureaucratic communication in our Federal system (some may consider that to be also outside human control).

10. Certainly, an acute catastrophe can trump bureaucratic impediments. Witness the way in which the Port Arthur massacre disposed of years of obfuscation and obstinacy concerning firearm control at a national level. However, it is submitted that aspects of both Tracy and Port Arthur are applicable to the solution of a chronic catastrophe.

11. An experienced leader with a track record of major organisational achievement should be recruited from public or private sectors on a fixed term appointment of 5 years to establish and direct a Task Force with a brief of setting in place a program for the outplacement of younger people from nursing homes. He or she should have direct access to a senior Australian cabinet minister. The Task Force should have resources to recruit members with specific knowledge of the problems it is to address. Recruitment should be in adequate numbers, geographically comprehensive and on a fixed term contract basis.

12. Apart from people contracted to the Task Force, the participation of at least two other categories will increase, and perhaps be essential for, a successful outcome. The first group will be volunteers. As will be indicated in outlining below what the Task Force needs to do, both existing problems and their solutions are often locality-specific. There are many in the community with commitment and local knowledge about both (many of them will have put submissions to the References Committee). Considerations of expediency, and of economy, require that the Task Force not devote time and resources to reinventing wheels. Recognition that payment for service, while it imposes responsibilities, need not preclude contribution to a goal as equals is necessary for full use of volunteers'contributions

13. The second essential additional group of participants are Members of the House of Representatives As with the people referred to in the preceding paragraph this participation will, of course, be voluntary. MHRs are uniquely well placed to be aware of local circumstances in their electorates and, if fortune shines on them, to be around beyond the lifespan of the Task Force. They are in a unique position to intermesh between their electorate community and the Australian Government In the unlikely event that any MHR declines to participate, other arrangements can be made. It can not be too strongly emphasised that the invitation to participate must be extended to al MHRs, irrespective of party political affiliation. Inclusion of Members in the project, and probably the success of the entire Task Force, will be jeopardised if anyone seeks to make political capital out of it. Those who have had some involvement with efforts to improve the circumstances of younger people in nursing homes are well aware that there are no votes in it, and that's the way it should remain.

14. What precisely is the Task Force to do? In summary it should consult nationally, at the level of individual communities, prepare recommendations for action at the level of specific communities and provide time scales with costings (more detail can be provided but is not done so here in order to constrain the length of this late submission). Local volunteer groups and local MHRs are likely to be in the best position to identify people to whom Task Force members should listen, to provide an account of local facilities and to prioritise local deficiencies in facilities and/or services. It is likely that many local communities have already given attention to possible solutions to their specific problems.

15. Recalling paragraph 5, the needs of individual ABI patients (but this point is likely to be equally applicable to other groups of younger residents in nursing homes) vary from patient to patient in line with the medical condition of the resident, the composition and circumstances of the immediate family, the locality etc. etc. The message from this for a Task Force as proposed above is that any uniform National solution to the problem of younger people in aged care facilities can be guaranteed in advance to be a bummer. In some instances, provision of adequate funds for house modification, allocation of sufficient hours of home care and of parental respite may permit a young resident of a nursing home to renew a rewarding social life at home. In others, the leasing of a group house with live in care may achieve the same goal for several people from a nursing home. Again, in other instances, construction of a purpose built facility staffed to care for individuals with high dependency needs may be the most appropriate solution. Whenever it is possible to determine the wishes of the younger person in an aged care facility by direct discussion, these should invariably be respected (in some instances, this may lead to continued residence in the facility).

16. Whilst the problem has to be addressed primarily at a local level, it should be recognised that some communities (and electorates) may have a disproportionate representation of younger people in nursing homes. Some acute care facilities have been quite ingenious in locating placements for their “placement problems” (a.k.a. patients) in distant facilities. Consequently, the release of young persons from an aged care facility in a city may entail the development of solutions that enable them to return to a home town accessible to their family and friends.

17. This submission has not touched on costs. Funding of the Task Force itself should be regarded as an investment in gaining accurate information on the needs of individual Australians living with disabilities. Funding of the recommendations of the Task Force can only be estimated when costings of individual unmet needs are aggregated at a national level. However, it can be confidently asserted, in advance of that exercise, that implementation of any recommendations will provide some cost savings. If this is recognised (and new costs and new savings will often fall on different budgets), net costs of offering an improved quality of life to a very disadvantaged group within our community will be appreciably less than gross estimates imply.

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Canberra, 30/01/05