

GIPPSLAND CARERS ASSOCIATION Inc.

Association Incorporation Number A0035748T

ABN 20547 306 121

email jtops@vic.australis.com.au

Jean Tops – President
PO Box 937, Moe 3825
Phone/Fax: 5127 1904
Mobile: 0402 650 375

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

29 July 2004

Dear Sir Madam,

RE: Inquiry into Aged Care

The Gippsland Carers Association ask you to accept the attached Submission to the above inquiry on behalf of elderly, frail and long suffering unpaid family caregivers with our earnest appeal for radical reform of a failing system.

It is our view that an inquiry into aged care services will be incomplete without due consideration of the affects those services have on large numbers of caring families who rely on them for support when it is needed.

The most compelling argument for reform lies in the demarcation line between aged care services funded and provided under federal policy and disability services provided by the states and territories under the Commonwealth, States and Territories Disability Agreement (CSTDA) funding arrangements.

The latter agreement has given rise to the practice of 'age discrimination' in the provision of disability services and policy directions that have created large pools of frail, elderly, unpaid family Carers struggling to care for adults with dependent disabilities aged less than 65 years.

This submission deals specifically with the results of these separate policies, which fail both the person with a dependent disability and the frail and aged Carers who provide them with a supported accommodation service worth Billions of Dollars to the national and state economies annually.

Yours sincerely,

Jean L Tops
President
Gippsland Carers Association Inc.

SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE
INQUIRY INTO AGED CARE
Parliament House Canberra ACT 2600
29 JULY 2004

- a) Preamble: This Submission to the above Inquiry is for and on behalf of the Gippsland Carers Association Inc. We aim to represent all unpaid family Carers of persons with a dependent disability, handicap or frailty and living in the Gippsland Region of Victoria.
- b) We ask you to note that we are possibly the only regional Carers Association in the country and that we are wholly self managed and funded by family Carers for family Carers. We exist because we have a felt need to have a rural and regional voice in the planning and delivery of support to families who are for the most part un-supported or poorly supported in caring for dependent Australian citizens.
- c) We make the point that the Department of Aged Care and Health are to be congratulated for funding Carers Associations at the federal and state level for the aged care sector of unpaid family Carers. We further make the point that the families of people with disabilities under the age of 65 years have yet to receive family advocacy funding that reaches to the states let alone the regions. (We acknowledge and applaud the Minister for Family and Community Services for funding the establishment of the National Families Carers Voice, which is still in its infancy.)
- d) Family caregivers are critical to government in their contributions to the welfare of not only aged citizens, but also to citizens with dependent disabilities of all ages. We do not need to elaborate on this factor, which is abundantly clear in ABS Disability and Carer Surveys and by the AIHW Report on Australia's Welfare 2001, amongst others.
- e) The AIHW report clearly accepts a contribution by 2.5 million unpaid family Carers, of not less than \$27 Billion annually. A figure we would argue, which is highly conservative (and recognised as such in the findings) because the rational used to measure the value of this care was a benchmark 38 hour week at personal carer rates of pay. This discounts entirely the 24 hour, 365 day/year care provided freely by at least 650,000 primary carers.
- f) Statistically then, we are concerned for the welfare of some 24,000 Gippsland families caring for dependently disabled relatives at home. This includes the care of children, adults aged less than 65 years, and elderly persons aged over 65 years.
- g) It is this 'age' demarcation line in relation to the delivery of services, which is of the major concern in relation to this Inquiry. Family caregivers face daily, the issues confronting not only the elderly who need care and support, but, also the system of support to and for elderly primary Carers of younger persons with disabilities.

- h) We contend that current federal policy of support for aged Australians dismally fails the frail and elderly Carers of younger persons with dependent disabilities; and
- i) We contend that the Commonwealth State and Territories Agreement (CSTDA) has failed elderly family caregivers; and
- j) We contend that the HACC Funding system, intended to support the maintenance of elderly and disabled persons at home dismally fails elderly Carers of younger disabled persons; and
- k) We contend that the flawed de-institutional policies of government are not only failing disabled persons themselves, but also fail the primary caregivers burdened with the myriad pieces of shattered family life that ensue. The induced health deficits and financial burdens that unpaid caring imposes are hidden costs that governments choose to ignore. State disability policy directly affects ageing Carers and the inappropriate placements of young disabled relatives in age care facilities demonstrates not only the failure of policy, but, most clearly articulates the reason for the existence of so many frail aged Carers today.
- l) How well able, and how willing unpaid family caregivers are to continue to bear the major responsibility for elderly and disabled relatives is largely dependent upon how well governments fund and provide support services.
- m) Such support to families is, we contend, the Corner Stone to all Policy in relationship to Aged Care facilities, their capacity to meet demand, and their capacity to deliver positive outcomes to frail elderly citizens.

This submission then aims to deal with the two most critical Terms of Reference of the inquiry.

1. The appropriateness of young people with disabilities being accommodated in residential aged care facilities.
2. The adequacy of Home and Community Care programs in meeting current and projected needs of the elderly.

Younger people with dependent disabilities in residential Aged Care Facilities

- I. The AIHW publication Australia's Welfare 2001 reports that there were 6,151 younger persons with dependent disabilities accommodated in aged care residential facilities in year 2000 (pages 121/293).
- II. The principal reason for these placements is the fact that the states and territories, who have responsibility for the welfare of persons with disabilities aged less than 65 years, have abandoned their responsibility for these persons.
- III. Under the CSTDA, states and territories have an obligation to provide age appropriate facilities that deliver a quality nursing and personal care service of at least the level offered to elderly citizens in the aged care residential sector.

- IV. States and Territories that fail in this obligation; do so because they have swallowed the de-institutionalisation rhetoric metered out by senior bureaucrats as an excuse to abrogate their responsibility, and to cost shift the obligation to aged care.
- V. It is our contention that states and territories are practising 'age discrimination' in the choices of supported accommodation offered to persons with dependent disabilities aged less than 65 years. The one-size-fits-all group home Model of residential accommodation whilst suitable for some people with dependent disabilities, denies any other choices and falls far short of the 24 hour, nursing level of care, required for persons with profound disabilities.
- VI. The overwhelming cost of the 5/6 bed group home option (\$100,000 per bed in Victoria) compared to the cost of aged care residential services is a further disincentive for states and territories to hold up their end of the CSTDA bargain.
- VII. It is our contention that the state of Victoria (at least) have failed to meet the requirements of the Intellectual Disability Services Act 1986 to 'fund, plan and provide accommodation and support services to 'meet the needs' of intellectually disabled Victorians.' Placing young persons into aged care facilities is a tragic outcome of policy.
- VIII. This failure has led to a further tragic situation where there are more than 4,000 Victorians aged less than 65 years on the DHS supported accommodation service needs register (SNR). Over half of these people (2,077) are rated as urgent. The handful of people, lucky enough to obtain a supported residential service, wait on average for 140 weeks for a placement (Vic Council Hansard Q 880/2736 22 April 04).
- IX. Almost all urgent cases of persons on the SNR are living at home with frail, aged parent, siblings, and even grandparent primary Carers, and this is an outrage.
- X. The impact on aged care services, of failed CSTDA funding arrangements will continue to increase as states and territories shirk their obligations to provide age appropriate residential services to people with dependent disabilities. This will force the situation where more and more young people are 'dumped' into aged care residential services.
- XI. The reality of state government policy that claims people with disabilities are provided with choices in living options is manifest in the fact that Victoria did not allocate a single dollar to bricks and mortar in order to provide residential care for even those on the urgent SNR.
- XII. It is a simple maths to say that moving over 6,000 young persons from aged care facilities into 'age appropriate' nursing level of care facilities, will free up the same number of aged care beds for those elderly citizens now waiting in acute hospital beds for a vacancy in the aged care residential system.

The adequacy of Home and Community Care programs in meeting current and projected needs of the elderly.

- I. The multiple pressures of an ageing population, rapid hospital discharge of people to the care of family, and the deliberate policy of maintaining persons in the family home as long as possible, have enormous impact on HACC services.
- II. Family Carers are facing an ever-increasing pressure to care at all costs, against an ever- dwindling supply of care support services due to demand outstripping supply.
- III. Upward cost pressures are also affecting partners in the HACC scheme with concerned local government increasing their contributions to the detriment of other ratepayer-funded services in many cases.
- IV. Critical factors affecting the frail and ageing Carers of younger persons and children with dependent disabilities is the heavy weighting of HACC services to the frail aged recipient. This federal/state conundrum over responsibility and the resultant age discrimination the divide creates, puts frail and elderly Carers with younger dependent persons in their care 'on a dividing fence' that neither tier of government accepts responsibility for.
- V. Pivotal in the capacity of families to continue to provide the vast bulk of 'supported accommodation and personal care is the need for primary caregivers to have access to respite services sufficient to enable rest and recuperation and the ability to continue for protracted periods of time.
- VI. It makes economic sense to provide facility-based respite care facilities that offer at least annual R&R to full time Carers in line with paid workforce expectations. This cannot be achieved unless and until, all levels of government offer dedicated respite care facilities designed for the purpose. It is a fact that offering respite in residential services is not palatable to many frail elderly persons who fear of being left there by families.
- VII. Similarly, it makes economic sense to provide dedicated respite care facilities for primary Carers of younger persons with dependent disabilities, particularly where those Carers are themselves elderly and /or frail. Such facilities have been black-banded by the Victorian government as "institutional" and will not be funded.
- VIII. Against this level of demand pressure, we note that Respite is not a target for growth funding in the current three Year HACC agreement; and we are moved to ask why? Surely, the most vital necessity in this whole debate is about funding services that keep the unpaid care relationship at maximum strength in order to keep residential care at a minimum.
- IX. There is no economic sense in exerting maximum pressure on primary caregivers as the resultant breakdown of family; adverse health impacts and general wellbeing decay only lead to greater overall cost to the taxpayer in welfare, health, accommodation, and participation costs.

- X. These factors raise the very real question of the validity of the CSTDA, the effectiveness of HACC services in meeting the support needs of primary caregivers and the very real need to reconsider both.

Recommendations:

- I. That the Senate Community Affairs References Committee condemn the practice of placing young citizens into residential aged care facilities and demand an immediate review of the CSTDA to ensure the elimination of this practice by states and territories who abrogate their responsibility in this matter and . . .
- II. Implement an immediate review of the funding arrangements between the commonwealth, states and territories, local government, service providers, and families. Objective of the review is to ensure the eliminated of AGE DISCRIMINATION from the provision of residential services, community care services and Carer support services.
- III. Such a review must include aged care residential services, disability supported accommodation services, in-home support services, and facility-based respite services for all age groups, including children. Such a review should include all Aged Care funding models including HACC, and Commonwealth Carer Respite and all Disability funding models including the CSTDA.
- IV. That the Senate Community Affairs References Committee recognise the exploitation of unpaid family caregivers as detrimental to the national good and....
- V. Take steps to ensure that the valuable \$multi-billion contributions of unpaid family Carers of the frail aged and disabled persons are preserved for future generations by...
- VI. Supporting the introduction of “Carer entitlement Legislation” which will ensure that the necessary supports are made available for family caregivers to continue in the caring role and/or relinquish the caring role in a timely manner to avoid adverse impact on any, or all members of the family unit.

The Gippsland Carers Association commends this recommendation to the Committee and asks that you hear the voice of the families directly affected by your decisions in this Inquiry.

We express our willingness to appear at Hearing if so desired by the Committee.

Submission prepared by: Jean L Tops Life-long and aged parent Carer and ..
President - Gippsland Carers Association Inc.