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Submission No. 660
(Inq into better support for carers)

**Submission
TO**

**Australian Government
Standing Committee on
Family, Community, Housing and Youth**

Inquiry into

Better Support for Carers
4 July 2008

Submitted by: Gippsland Carers Association Inc
On behalf of family Carers of
Persons with dependent disabilities

Address: PO Box 937, MOE 3825

Contact: Jean L Tops – President
Pam Trew - Secretary
Phone/Fax 03 5127 1904
Mobile: 0402 650 375
Email: gippscarer@vic.australis.com.au

AUSTRALIAN GOVERNMENT INQUIRY INTO BETTER SUPPORT FOR CARERS

The Gippsland Carers Association Inc is a wholly self funded and self managed information, peer support and advocacy, dedicated family carer organisation, consisting of family and community members providing unpaid accommodation, care and support to persons with a disability, handicap or frailty.

The Association is representative of some 24,000 unpaid family Carers of people with disabilities throughout Gippsland in Victoria. However, our influence stretches far beyond the region itself. We are actively involved in networking with caring family groups across our state and nationally as a part of the National Carers Coalition.

A critical factor in the formation of the Association is the lack of commitment of successive governments over time, to ensuring that all families caring for persons with dependent disabilities receive support via their own funded family support and advocacy services. By political design, this neglect occurs, despite the fact that families provide more than 93% of the supported accommodation and personal care needs of persons with dependent disabilities across the entire nation.

We were established in 1997 and rely entirely upon the support of caring families, local service clubs, local government, philanthropic grants, and generous citizens.

Governments are continually looking towards the funded Disability Services Sector and the Funded Disability Advocacy Sector, when seeking to examine the delivery of services to disabled citizens and the families who care for them. It is imperative therefore that the Committee understand how this leaves the vast majority of unpaid family Carers out in the cold in every consultation process.

Because of this neglect, it will be a very difficult task for Carers to make their submissions to this vital Carers Inquiry.

A very real question to be asked by the Committee is 'how in the world unpaid family Carers will know about this inquiry when they have no funded voice to speak for their vast majority?' How in the world will unpaid family Carers know about this inquiry when so few have the resources to be on-line all the time?'

As a consequence of the isolation of caring families and the absence of a funded family advocacy network Gippsland Carers Association have co-operated with the National Carers Coalition (NCC) Submission as co-authors and fully endorse the sentiments and recommendations the NCC submission contains.

We strongly believe that all families have a right to be included in the general activities of the community irrespective of their caring role and responsibilities to Australian citizens with dependent disabilities and irrespective of their age.

We believe unpaid family Carers and those for whom they care are entitled to a decent standard of living, an adequate income and the right to enjoy all the benefits available to non-caring and non-disabled peers including the right to paid work.

We believe that Family Carers:

- Are citizens with equal rights to legal, financial, social and culturally normative lives free from discrimination, exploitation, isolation and prejudice.
- Have the right to access supports that sustain their ability to be fully participating members of society within the full range of choices available to the general community
- Are entitled to the utmost respect and full involvement in decision-making, including Policy and program direction and planning.
- Unpaid family Carers have the right to choose **NOT TO CARE** and the right to expect that age appropriate and normative alternate care will be provided to dependent family members.

The caring families of Gippsland thank the Committee for the **rare opportunity** to be heard by the decision-makers of our nation. We express our deep appreciation for your decision to hold this inquiry into Better Support for Carers. Our prayerful hope is that positive outcomes for caring families and people with disabilities will be achieved.

We intend to make our case for urgent reform, based upon the complete failure of the system to meet even the urgent requirements of carers and their families for the basics to sustain equality of life with non-disabled Australian citizens and their families.

We make the critical point that the issues we have raised jointly with the National Carers Coalition have been repeated again and again and again to Inquiry after Inquiry, to consultation after consultation and review after review.

We therefore ask the valid question of this Committee, will you ensure that the Australian Government will be Doers of Reform and not Sayers of Reform to Better Support Carers?

THE STAKES ARE HIGH FOR UNPAID CARING FAMILIES.

We would like the Committee to know that the vast majority of families care for disabled loved ones first and foremost, because we love and care for them. We also want you to know that we are very resentful of the fact that successive governments and the bureaucracy that rules our lives have taken extreme advantage of this fact.

The industry that prospers from delivering a support service to people with disabilities has a love, hate relationship with the very families who are the sole reason why countless thousands of persons with dependent disabilities have a roof over their heads to this very day.

Nothing is more painful for a caring family to bare, than the knowledge that our contribution to the welfare of our dependent relatives and our contributions to society are recognised only by lip service, and our silence is engineered.

There are no paid professionals writing this submission to the Committee. Such support to the vast majority of caring families is non-existent. We want you to know therefore that our plea for dramatic reform of the failed Carer system is straight from the heart of grassroots family caring. Please listen to us.

SUPPORT AND ADVOCACY – WHY CARING FAMILIES DONT HAVE IT?

The Commonwealth directly and the States and Territories through the CSTDA fund Disability Advocacy services at the National, State and Regional level for people with disabilities themselves, and that is the right thing to do. The Federal Department of Aged Care also funds Carer Associations at the National and State level as Information and Resource Services. Some states fund family advocacy for the families of children with a disability up to age 18 years, Victoria being one of these.

But, no-one funds disability family advocacy for the families providing over 93% of all accommodation, personal care and support to persons with dependent disabilities aged 15-64 years and we do not understand why we are being so discriminated against?

Even our detailed joint submission to the current government budget process January 2008 – National carers Coalition, for the funding of a regional, state and national disability family advocacy network has been ignored.

Population statistics on the incidence of disability, as articulated by the ABS in general population census, make it clear that on a percentage basis the breakdown of population can be literally determined as 20% children aged 0-17 years, 67% adults aged 18-64 years and 13% aged persons aged 65 and over. By far the largest cohort of persons being 18-64 years where over 700,600 people with a severe or profound disability are named as the 'potential population' for needing disability support services.

The absence of any credible recognition of the role and rights of caring families as vital to the welfare and wellbeing of disabled persons condemns the CSTDA and its administrators for shutting families out of the decision-making process. Current funding and operations are self serving of senior public employees (the Bureaucracy) and the governments of our nation who ignore the voice of families clamouring for reform, in order that bureaucracy may foster their own brand of disability service exclusively and continue carer exploitation and neglect.

Most recent evidence of this exclusivity policy in Victoria can be found in the passage of the Disability Bill 2006, which deliberately excludes any recognition of Carers in direct conflict with the CSTDA Multi-lateral Agreements and in spite of strong evidence that this action isolates and discriminates against Victorian Carers.

This 'as-bold-as-brass' exclusion of Carers from the Victorian disability Bill, was 'marched' through parliament by a government in absolute control of both houses of parliament and a bureaucracy bolstered by its own community inclusion rhetoric. These actions, apposed by service providers and family support networks, were supported by the funded disability advocacy sector in an open rejection of family carers.

Since unpaid family Carers provided 93% of the supported accommodation required by the most dependent of all disabled peoples, the role of disability advocacy must seriously, also be questioned because nothing substantial has changed in decades of neglect of persons with dependent severe or profound disability.

It is a sad fact that paid disability advocates actually oppose the call by families for people with dependent disabilities to have the same rights as every other citizen to a home of their own, and they appose the very idea that the same range of accommodation choices be also available to them as is available to everyone else.

Many families caring for disabled loved ones have spent a lifetime in the caring role. Some of us can trace our involvement and our recollection of changes within the disability services sector back for decades. Back to before, there were any CSTDA funded services, back to the days when the only alternative to families caring, was to give up a disabled child to the care of the state. Large scale congregate settings in capital cities and some major regional Centres, that came to be known as “Institutions” for the mentally Retarded and the obscene lack of appropriate care in such places, became the catalyst for the reforms of the 1980’s, led predominately by families and with support from the Media.

Thus, the decision-making by the bureaucrats charged with reform responsibility, came to be; close the ‘demonic institutions’ at all costs and put people with disabilities back into the community where they belong. The commencement of the Group home era heralded the introduction of new legislation driven by the jargon of ‘community inclusion,’ ‘normalisation’ and ‘integration’ and person centred planning became policy.

The irony of the argument for the bulk of dollars for disability services to be spent on this exercise at the expense of support to families doing most of the work, is that the vast majority of dependently disabled persons (some 85%) have never seen the inside of an ‘institution’ because they have always lived with family. To this day, over 93% of caring for severely and profoundly disabled persons takes place in the family home.

To families struggling to cope with little or no support under the veiled promises that once those ‘institutions’ were gone, governments would be able to provide more support to families directly, has now become folk-law.

Clear evidence of the failed decision-making by Commonwealth, State and Territory government bureaucracy is the fact that such small numbers of persons as those domiciled in congregate care settings at the outset of reform remain an issue to this very day, almost 3 decades on and with no end in sight. The evidence of the crisis left in the wake is everywhere.

Throughout the 1980’s the issues of states and the commonwealth both funding the delivery of disability and aged care services came to be a punching bag for each to blame the other for failures. The inability of either regime to meet the increasing demands for support services by the disability community and by their families becomes more and more obvious. When all else fails policy-makers re-invent themselves and the CSTDA became the sacred icon of a brave new world of the 21st Century.

Sadly for caring families and for disabled people themselves, the advent of the CSTDA has not stopped the state/Territory/Federal Government ‘Blame Game’ and worse still the wrangle is now used by all levels of government to excuse themselves from the fact that unmet need for supported accommodation services is ‘out of control’. The bureaucracy charged with responsibility for managing the crisis is also out of control.

Gippsland Carers Association made detailed submissions to the Senate Inquiry into the Funding and operations of the commonwealth state and Territory Disability Agreement (CSTDA) 2006.

Our submissions included detailed proposals for the introduction of Population Based Benchmark Funding (PBBF) of disability services to mirror the PBBF that has existed in aged care for decades. The senate CSTDA final Report 2007 recommended that benchmark funding be introduced.

The Senate made as its unanimous Primary Recommendation that “The Commonwealth and the States provide substantial new funding for the next CSTDA” due for signing 1 July 2007. The Inquiry also said: “The burden of caring upon families was crushing and unreasonable”

In spite of the fact that the Rudd Government came to power on a commitment to “end the blame game” and to “introduce population based benchmark funding to disability services” there is no commitment to act now.

The current CSTDA negotiations have pushed any benchmark funding out to at least 2012. Many carers will be broken or dead by the time any meaningful changes occur.

The federal government promise that increased funding made available by the previous government would be matched \$ for \$ by the states is a joke when we see that the states have used their forward estimates to claim matching dollars.

The real kicker for carers is that the \$1.9 billion (loudly proclaimed) over 4 years can hardly be called “substantial new funding” when less than 7% of 706,600 people with a dependent severe or profound disability currently have an accommodation support funding package, and only some 15,000 of these actually have a government funded roof over their heads.

The reality of population based benchmark funding is that some \$7billion of funding on top of the current national spend of around \$4billion is needed to provide for only 1.8% of the population aged 17-64 to gain access to a support service of some kind.

The kicker for carers in the wake of the crushing and unreasonable burden on caring families is that 1.6 million of us care for someone with a disability aged less than 65 years old and over 55,000 of us are parents caring for an adult child aged over 35 years. This “first step” by the Rudd Government can hardly be said to “relieve the crushing and unreasonable burden on caring families can it?”

Population benchmarks make the stark reality plain

The scope of the issue of population-based benchmark funding of disability services would seem to be overwhelming if benchmarks were applied in the same manner as the formula that currently exists to fund aged care, i.e. 108/1000 places/packages of the population aged 70 plus adjusted annually. To determine how this formula applies to aged care we need to look at the incidence rate of S&P disability in the aged and determine how this influences the funding benchmark. The incidence rate of S&P disability in the aged is 22.5% for all persons aged over 65 years. (ABS Survey of disability aging and Carers 2003). The percentage of the total population aged 70+ is 9.3% (Report on Gov Services 2006). The aged care funding allocation based upon the current projection of 108/1000 is set out in figure 2. Below:

Fig2. Table derived from figure 12A.1 Report of Gov Services 2006

Pop 70+ Jan 2007	% of total population	% Severe & Profound incidence rate	108/1000 benchmark for bed places or packages
1,892,800	9.3	22.5	204,422 places/packages (a)

(a) Aged care allocations of beds and packages is currently = High care 40.8%, Low care 42.4%, CACP's 16.0% and EACH 0.9%.

Comparing the over 65 years of age incidence of severe/profound of 22.5% with the 15-64 years incidence of severe/profound of 3.9% we create an incidence ratio of 5.7 / 1. That is 5.7 units or care packages for 70+ populations to every 1 unit or care package for the population age range 15-64.

This means that the disability services sector population benchmark should be 18 /1000 of the population aged 15-64 years.

Furthermore, it is a logical step to look at the current planned aged care allocation of 108/1000 of the population aged 70+ and say this figure equates to 10.8% per 1000 or approximately half of the severe/profound incidence rate of 22.5%.

This percentage allocation when applied to the people with severe/profound disability benchmark of 18/1000 becomes 1.8% per 1000 or approximately half of the severe/profound incidence rate of 3.9% for under 65 year olds. Figure 3: shows the number of beds/packages to be applied to disability services utilising the 18/1000 benchmark as described above.

Fig3. Utilising ABS – DAC 2003 population chart-4430.0

Pop 15-64 (a)	% of total population	18 /1000 benchmark for bed places or support packages
13,273,437 (b)	67 (c)	238,914 places/ packages (rounded)

(a) Calculations based on a 2003 overall population of - 19,811,100 ABS

(b) Severe & Profound incidence rate of 3.9% (c) population aged 15-64 years

The benchmark formula is based upon a similar ratio to those in aged care (see fig 2) i.e. High care beds/packages 30% - Low care beds/packages 30%; and Community Access packages 40.0%. The ratio changes are to reflect higher demand for community support for people with disabilities. Each category will provide for facility based and home-based respite as a priority. Application of the benchmark funding formula and High/Low/community packages will be as set out in the chart below.

Fig (4)

18/1000 benchmark of Pop 15-64	30% High Care support packages	30% Low Care packages	40% community Support packages	Total Recurrent
*238,900 (rounded)	71,670	71,670	95,560	
High Care \$83,000 Per bed/package	\$5,948,610,000			
Low Care \$45,000 Per bed/package		\$3,225,150,000		
Community Care \$18,800 per Unit			\$1,796,528,000	\$10,970,288,000

- National average costs for accommodation support services are as follows:
Group homes: \$83,098 per service user - Institutions and hostels: \$74,461 per service user,
Community based support: \$18,883 per service user (AIHW Minimum Data-set 03-04).

The Population Based Benchmark Funding proposal put forward by Gippsland carers to the Senate Inquiry is attached to this submission for the committee's information and support.

The reality for carers of people with dependent disabilities is that unless and until adequate funding is provided to ensure that the people we care for in our own homes have the support services required to give both them and their carers a reasonable life then the burden will overcome unpaid care as a future prospect.

Young families today find they must have both parents in the paid workforce to have a roof over the families head. They will NOT put up with the crushing and unreasonable burden we all share.

Unpaid family carers are discriminated against and exploited in the most disgraceful manner by governments at all levels.

- We are not a part of the Rudd governments "working Families strategies" because we have no recognition for the work we do. We are the hardest working of all families we just don't get any pay, no annual leave, no sick pay, no days off, no superannuation, and no retirement plans.**
- We have no legal rights and no entitlements to pay, conditions or support services.**

We join our recommendations with those of the National carers Coalition and beg the committee to hear what we have to say. Carers do wish to continue to care for loved ones who have dependent disabilities, but we cannot continue to pay the price being asked of us.

The Australian Institute of Family Studies Report –The Nature and Impact of Caring on Families says it most clearly:

“Carers have significantly worse mental health problems and vitality and higher rates of depression than the general population”

Please hear what we are saying to you and act to “make a difference” by ensuring we receive “Better support for carers” We ask you to give caring families the networks of support that they are begging for, ease the crisis, raise the bar, and help the carers who contribute over \$41.2 Billion a year to the national economy (Australia’s Welfare 2007)

Recommendations –

That the Committee for Family, Community, Housing and Youth recommends:

1. The Federal Government immediately make funding provision for the implementation of a Disability Family Advocacy Network, commencing with grass roots regional bodies who will nominate their state and federal peak bodies as articulated in our submission addendum.
2. The Federal Government immediately legislate for Carer Rights, including the right to care or not care , the right to Carer Assessments and Entitlement to Support Services.
3. The Federal Government legislate for the introduction and funding of Population Based Benchmark Funding of Disability and Carer Support Services as a matter of **First Order Priority**.
4. The Federal Government immediately legislate to ensure that all full time family carers have access to **means test free** and **income tax exempt** carer payments that will include a cost of care component with no 25 hour work/study/ volunteering rule.
5. The Inquiry by the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs into financial security for carers and seniors make a stand-alone report on financial security for Australia’s 2.6 million carers to the Henry Commission Review of Australia’s Future Tax System.
6. The Federal Government ensure that service agreement negotiation with the states and territories foster the provision of long day care for older children and adults with dependent disability aged less than 65 years to facilitate paid work opportunity for carers and to relieve the burden of caring on stressed families.
7. That the Federal Government ensure people with dependent disabilities have Legislated entitlements to assessments of need and access to accommodation and support services to meet those needs.

We commend our submissions to you and would be pleased to have the opportunity to meet with the committee to discuss ‘better support for carers’ in detail.

For and on behalf of the unpaid family carers of Gippsland.