BREAKING THE SILENCE ON UNPAID FAMILY CARING

# Supplementary Submission
# Senate
# Community Affairs Committee

## Hearing in Victoria
## for the Inquiry into

# The Funding and Operation of the CSTDA
## *October 2006*

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

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## Senate Community Affairs Reference Committee
## Funding and operations of the CSTDA

### Thank You

The Gippsland Carers Association expresses our gratitude to the Senate Community Affairs Committee for the invitation to give evidence at the Senate CSTDA Inquiry Hearing held in Melbourne on 28th of September 2006.

Thank you for the opportunity to make a supplementary submission on the issues discussed during our presentation and on other matters raised throughout the day.

We apologise for any typing or syntax errors due to constraints on our resources, and note that we would like to provide comment and or clarification on the following matters:

1. Who are the 'Potential population" and why they are critical to this Review?
2. The captive population of high-end service users, versus those who have little or no service?
3. The waiting list, myths and mysteries?
4. The conundrum of why disability services must be managed locally (state based) but aged care services do not?
5. The impact of Workcover Regulations/ Occupation Health and Safety Regulations, upon the family and their home?
6. The debate about a national catastrophic injury insurance scheme?
7. The myth about disability family advocacy, regional responsibility and inclusion?
8. Population Based Benchmark Funding and what it might cost?

## 1. Who are the 'Potential population" and why they are critical to this Review?

In order for there to be reasoned debate about **unmet demand** for disability services, within the context of the CSTDA Review there are a plethora of Surveys and Reports commissioned or funded by government that may be relied upon. Most critical of these are the ABS Survey of disability, ageing and carers (DAC) 2003 and the annual Report of the CSTDA Disability service services dataset published by the AIHW, the latest of these being for 2003-2004.

All population data collected by ABS, including the National Population Sensus rely upon a self reporting format and it is therefore logical that the results of the ABS Survey of DAC is as much to be relied upon as the national sensus for planning services for all Australians. The AIHW therefore relies upon the ABS/ DAC survey data to calculate the number of persons who have a severe or profound disability.

The ABS/DAC survey estimates the number of persons who have a disability by degree of severity based upon international classifications of mild, moderate severe or profound disability and that degree of disability is measure upon the individual's ability to perform or participate in all activities of daily living including personal care, schooling, employment, etc. The ability to perform core activities of daily living is then applied to determine degree. Core restrictions means a person always or sometimes needs help with the three basic activities of self care, mobility and communication.

- Profound disability = Always needs help with core activities
- Severe disability = Sometimes needs help with core activities

The AIHW in compiling the CSTDA Service Users minimum dataset map concludes that all persons with a severe or profound disability may be potential users of CSTDA service if their informal support systems fail for any reason. The 'POTENTIAL POPULATION' therefore becomes all persons with a severe or profound disability based upon the national average incidence rate for persons aged 0-64, currently estimated by ABS to be 3.9% of the total population of that age.

*Note: The AIHW in compiling the CSTDA minimum dataset of service users points out that up to 18% of all users are persons with a mild or moderate disability, and this must be taken into account when comparisons are made.*

It is the comparison of the numbers of persons in receipt of a CSTDA funded disability service when compared to the "Potential population" of persons with a severe and profound disability only that is the critical factor in considering UNMET NEED in this Review.

*As the charts in our original submission show clearly only 4.8% of the "Potential Population of persons with a severe or profound disability were in receipt of accommodation support services wether in their own home, the family home or a government provided home of any kind.*

**Unless the Senate grasps the magnitude of this shortfall in the provision of services to people with severe and profound disabilities, it cannot legitimately address the unmet need issue or what needs to change in any new funding and delivery arrangements for disability services.**

## 2. The captive population of 'high-end' service users v those who have little or no service?

The recently released 2004-2005 AIHW CSTDA national data of service users has for the first time a credible comparison of 12 months data collection analysis based upon the 2003-2004 first full year collection. The comparison between the two full year collections tells a very significant story of how well or how poorly the CSTDA is dealing with unmet need, how many persons actually received any service and what growth rate (if any) applies to the current system.

## The High-End-Users of CSTDA funded services

By far the most significant pool of service users under the CSTDA are "High-End Users" of accommodation support with the bricks and mortar variety taking up over 52% of the entire Disability budget allocation each year. The following two tables show the growth in numbers of clients utilising accommodation support from 03-04 to 04-05

**Fig 1(a). (AIHW 2003-2004 CSTDA Table of service users per 1000 of the potential population )**

| **Service group** | NSW | Vic | Qld | WA | SA | Tas | ACT | NT | Total |
|---|---|---|---|---|---|---|---|---|---|
| | **Accommodation support** | | | | | | | | |
| No. of service users | 6,440 | 12,989 | 4,933 | 3,136 | 4,069 | 1,069 | 334 | 212 | 33,175 |
| Potential population | 229,183 | 165,315 | 134,671 | 69,074 | 52,114 | 17,004 | 11,248 | 8,986 | 687,710 |
| Service users/1,000 potential population | 28.1 | 78.6 | 36.6 | 45.4 | 78.1 | 62.9 | 29.7 | 23.6 | 48.2 |
| **Have NO Service** | **22,743** | **152,326** | **129,738** | **65,939** | **48,045** | **15,936** | **10,914** | **8774** | **654535** |

**Fig 1 (b). (AIHW 2004-2005 CSTDA Table of service users per 1000 of the potential population)**

| **Service group** | NSW | Vic | Qld | WA | SA | Tas | ACT | NT | Total |
|---|---|---|---|---|---|---|---|---|---|
| | **Accommodation support** | | | | | | | | |
| No. of service users | 5,980 | 13,199 | 5,034 | 3,371 | 4,550 | 1,128 | 338 | 212 | 33,787 |
| Potential population | 230,833 | 166,114 | 138,657 | 70,560 | 52,368 | 17,355 | 11,245 | 9,842 | 697,124 |
| Service users/1,000 potential population | 25.9 | 79.5 | 36.3 | 47.8 | 86.9 | 65.0 | 30.1 | 19.3 | 48.5 |

Clearly, the significance of this data is in the poor growth rate of accommodation support relative to growth rate in the potential population, and the tiny percentage of the target population per 1000 who have an accommodation support service of any kind.

[The charts indicate that the growth rate per1000 for accommodation support from 4.82% in 03-04 to 4.85% is minuscule to say the least, increasing the number of people receiving an accommodation support service by just 612 individuals nationwide. Hence, unmet need continues to grow!]

The breakdown of those who received a 'high end' service is more illuminating.

- Of the 33, 787 persons with an accommodation support services nationwide just 10,722 had a group home bed,
- 5,068 had a congregate facility bed; and
- 18,621 had living support somewhere else (mostly in the family home).

Fig 2. Expenditure on disability support services by Australian, state and territory governments (AIHW disability support services 2004-05 – Table 1-2:page 6)

| Service Group | NSW | Vic | Qld | WA | SA | Tas | ACT | NT | Au Gov | Au -Total |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | $ million | | | | | | |
| Accommodation Support | 652.8 | 515.5 | 233.3 | 158.3 | 142.7 | 54.9 | 27.5 | 13.8 | - | 1,798.8 |
| Community Support | 85.6 | 146.1 | 53.7 | 49.9 | 33.9 | 9.1 | 11.0 | 9.9 | - | 399.2 |
| Community Access | 125.8 | 165.9 | 61.3 | 22.5 | 16.2 | 13.2 | 3.6 | 2.1 | 7.7 (a) | 418.6 |
| Respite | 65.6 | 46.5 | 40.3 | 19.6 | 8.9 | 5.9 | 4.0 | 1.5 | 4.5 (a) | 196.7 |
| Employment | - | - | - | - | - | - | - | - | 324.5 | 324.5 |
| Advocacy/information & print | 8.0 | 7.2 | 6.6 | 2.2 | 4.0 | 2.0 | 0.9 | 0.1 | 14.1 | 45.1 |
| Other support | 2.1 | 41.5 | 3.9 | 14.3 | 13.6 | 1.0 | 1.7 | o.1 | 58.9 | 137.0 |
| Administration | 112.0 | 81.7 | 38.2 | 14.7 | 5.2 | 5.4 | 8.5 | 1.2 | 32.6 | 299.5 |
| Total | 1,052.0 | 1,004.5 | 437.3 | 281.3 | 224.6 | 91.4 | 57.2 | 28.8 | 442.3 | 3,619.4 |

(a) Aus Gov community access and respite are not funded under CSTDA. They are funded under the Disability Services Act – discretionary fund.

These figures clearly show that the small minority 'high-end' users of supported accommodation services are commanding in excess of 60% of the available funding i.e. NSW - 62% of all funding, Victoria- 51% of all funding, Qld 52% of all funding etc...

***The committee cannot escape the reality that disability services are simply scraping the bottom of the barrel in meeting the needs of people with dependent disabilities under the CSTDA.***

No amount of posturing by Mr Rogers, Executive Director for DHS Disability Services Victoria, will change the reality that the states CAPTIVE 5,053 persons who have a group home or "institutional" (their words not mine) bed in Victoria take up over 51% of the entire disability budget. This leaves crumbs and little more for anyone else, whilst excluding the vast majority altogether.

The group home system that delivers accommodation support at an average cost of $83,000 per person is not the end of the story for the ‘captive 5000.’ The majority of the group homes are run as a ‘dinner, bed and breakfast service’ Monday to Friday with all ‘tenants’ required to have an external day program. In an ATSS or similar program, this could be another $12,000 to $20,000 per person for the captive 5,000. These may also have access to a recreation and leisure option or community access option for who knows how much money?

The academics who continue to concentrate all efforts upon the ‘captive 5000’ are themselves complicit in the abject disregard expressed by anyone, for the long suffering families who continue to provide over 93% of all the supported accommodation needs, by asking for extra $dollars for these same people to “age in Place”.
**Unpaid family Carers want to ‘age in place’ but how can they, when they are prisoners of a discriminatory funding system that exploits them so shamefully?**

## 3. The waiting list, myths and mysteries?

As stated in our initial submission, the failure of state and Territory governments to maintain detailed and adequate waiting lists for services under the CSTDA is evident everywhere throughout the nation. We were disturbed to hear the Executive Director of Disability Service Victoria give evidence which appeared to hedge over the waiting times for supported accommodation and in-home support, presumably in order to downplay the extent of the problem in this state.

If the Executive Director of Disability Services is unaware of the extent of the unmet needs as evidenced in the waiting lists alone, then clearly this is hard evidence that the state managed system is in meltdown. Let us make the Victorian answer plain to the Senate Committee by reprinting here an extract from the Legislative Council Hansard on this matter:

**Questions on Notice Hansard Legislative Council Victoria Tuesday 30 May 2006**
**Community services: disability service needs register**
**7381. THE HON. BILL FORWOOD** — to ask the Minister for Aged Care (for the Minister for Community Services): Further to the answer to Question on Notice No. 4675 given in this House on 21 April 2005 in relation to the Disability Service Needs Register as at December 2004, with a total of 5081 individuals registered, and the answer to Question on Notice No. 5340 given in this House on 16 November 2005 in relation to the movement of 274 people onto the register and 196 people moving off the Disability Service Needs Register for the six months ending 30 June 2006, with an overall increase of 78 people, which would give a total of 5159 individuals on the Service Needs Register at 30 June 2005, how is this reconciled with the answer to Question on Notice No 5339 given in this House on 16 November 2005 with a total of 4761 individuals registered on the Disability Service Register as at 30 June 2005 i.e. a difference of 398 individuals.
**ANSWER:**
I am informed that: The Service Needs Register figures for 30 June 2006 are not yet available.

**Community services: disabilities services — accommodation**
**7389. THE HON. BILL FORWOOD** — to ask the Minister for Aged Care (for the Minister for Community Services): For the six months ending 31 December 2005 —
(1) How many people with disabilities waiting for shared supported accommodation obtained a place in a community residential unit.
(2) On average, for how many days had those people been waiting for a place.
(3) How many of those persons were relocated from congregate care to a community residential unit.
**ANSWER:**
I am informed that: For the six months ending 31 December 2005–
(1) The number of people with disabilities waiting for Shared Supported Accommodation and obtained a place in a community residential unit was 47.
(2) On average the people that waited for a Shared Supported Accommodation place who obtained a place in a community residential unit had waited for 218 weeks; however, these people had been receiving a range of supports and services.
(3) The number of people who were relocated from congregate care to a community residential unit was 2.

The above answers clearly support the argument that the current system is severely wanting and must be radically reformed. The advent of the Victorian Disability Bill 2006 is set to continue the masquerade.

## The Victorian government's 10 per cent for specialist services is an indicator of CSTDA Failure

It is abundantly clear from this government response to the questions in parliament that the disability system is failing people with dependent disabilities and the families who care for them. Further evidence appears in the public statements of the Minister for Community Services on who the government feels are the target for Victorian disability services. The minister claims that:

"In Victoria the government has identified a 10/90 split regarding specialist disability services:

- *The Disability Services Division of the Department of Human Services focuses on providing specialist disability programs which meet the needs of the 10 per cent of people who have more significant disabilities and need these services.*

- *The other 90 per cent of people with disabilities are mainly living in the community and are more concerned about improving access to buildings, housing, transport, education, jobs, health and other services. The new Office for Disability will tackle these important issues"*

*(Media Release 1 June 2006, Minister for Community Services, Office to improve access for people with disabilities)*

Furthermore, the Minister at the Public Accounts and Estimates Committee hearing on the 2006-07 Budget Estimates for the Disability Services Division reiterated this 10 per cent claim. *(PAEC transcript, Budget Estimates 2006-07, Minister for Community Services, 14 June 2006, p 18)* At the simplest level, the Minister appears to be saying that only 10 per cent of people with disabilities have disabilities that are more significant and need specialist disability services.

However, the ABS DAC survey 2003 actually identifies 178,400 Victorian people under 65 with profound or severe core activity limitation of the 627,800 all with reported disability. This is nearly 30 per cent of all people with a reported disability, and is 2.7 times the 62,780 which is 10 per cent of all people with disabilities aged less than 65 years.

## The smoke and Mirrors strategy on unmet needs registers

The Disability Department of DHS have made much of changing the Service Needs Register (SNR) to a Disability Support Register (DSR). They claim that is to ensure a person will have their support needs recorded rather that a service need. This we believe is smoke and mirrors for getting rid of people from the embarrassing waiting lists. Just recently we were informed by Carers that one of the largest state metro regions (20% pop) informed families that if their need for a service is not likely to be for two years hence, then they will not be placed upon the DSR at all. All future need for an accommodation service will therefore be eliminated unless urgent NOW.

The Victorian government has removed the need for mandated general service plans from the new Disability Bill. These were required for people with intellectual disabilities under the IDPSA Act, now redundant. The clear intention is to place the onus on people with disabilities themselves to ask for a service or a personal plan. *So much for forward planning to meet growing demand!*

## The Waiting List Answer - A National Disability Register

It is apparent that all state governments fail to maintain accurate waiting list data on which to plan for unmet needs. The is a clear and urgent need for the establishment of a Compulsory National Disability Register that will hold records similar to those held for the Cancer Register by the Health Departments.

Unless and until such a register is nationally in place, no amount of minimum dataset CSTDA reporting will make an iota of difference to unmet needs for those using services and will never capture those not using services. Unmet needs are not recorded in the Data collection for the CSTDA; therefore, unmet need cannot be measured.

There is no little or no future planning for support by people with disabilities or the families who care for them, because state governments like Victoria are determined to hide the reality of a crisis driven system.

## 4. The conundrum of why disability planners demand that the system be managed locally (state based) but aged care services do not?

*The defenders of the state managed disability system of service delivery, who claim that disability services are best provided locally and therefore must be provided by the states, constantly amaze us. This is another of those smoke and mirror strategies to limit the demand for equality and the removal of age based discrimination from disability services.*

The aged care system is funded and managed by the Commonwealth. They are doing an excellent job of placing nursing homes, hostels, village living, cluster apartments, intensive in-home support packages, in-home and facility-based respite into every town and city across the entire nation. This is in stark contrast to the ad hoc delivery of disability accommodation services.

Compare the Pair:- Some 220,000 beds in aged care services across the nation; and
Just 15,000 funded disability facility beds across the nation.

**How can the pathetic disability accommodation system be local, closer to home or 'better' than the aged care system? It cannot; and the argument does not hold any credibility does it?**

The Commonwealth does a far better job with aged care than the states do with disability services. It is clear that the application of population based benchmark funding to manage growth/demand and ensure a flexible, diversified and capital funded aged care system is a far superior and cost effective model of support to disabled persons aged over 65 years. It is time for a radical change.

The Victorian Community Visitors Annual Report 2005 on Supported Residential Services (SRS) has this to say about such services: "community visitors have reported for over a decade that there is a shortage of support and accommodation options for people who have ongoing support needs as a result of a mental illness or disability, pension level SRSs are often used to fill the gap."
and again;
" .. A significant proportion of residents of pension level SRSs are now younger people with a mental illness, intellectual disability or an acquired brain injury. Many have serious health problems or challenging behaviour....... alternate forms of housing and support for people with disabilities need to be created as a matter of urgency."

Mr Roger told the Senators at the Melbourne Hearing that his Department would not fund a 15-20 bed facility save that people chose this option and provided it for themselves, because they had individual care funding. This pre-supposes that in Victoria the government intends to opt out of bricks and mortar for disabled people altogether because they have already stopped funding new group homes.

**Mr Rogers is presiding over a hypocritical system that allows people with intellectual disabilities and acquired brain injury to exist in large numbers in squalid pension level SRSs of 20 to 40 beds, but won't allow disability services to fund decent facilities to take their place. How can governments allowed this disgrace to continue????**

The Executive Director of Disability DHS Victoria clearly indicated he certainly would not fund a 12 bed respite facility for the people of Gippsland as his answer to Senator Patterson's question on this matter clearly showed. Is this not clear evidence that supports our call for radical reform of this blatantly discriminatory state-based disability services system??

With a Gippsland population of over 240,000 and an estimated "potential population" of 9,360 severe and profound people under 65 there are just 18 respite beds for adults and 12 respite beds for children in the entire Gippsland region.

The adult respite beds are generally 'dinner, bed and breakfast' models that require people to attend their day program during week days unless it is holidays or special purpose arrangements. This means that only those who live close enough to the three adult respite houses, to get a taxi to their day program, can use the facility.

**A bizarre system such as this must be changed, if unpaid care is to survive.**

Compare the Pair: Aged Care 'v' Disability Care:

The aged care system provides high and low care facility-based accommodation that delivers some 220,000 beds nationally (2005 H&A Fact Sheet). It offers:

- Nursing levels of high care residential accommodation with strict controls on building and operational standards via accreditation.
- Supervision/low levels of personal care residential accommodation with strict controls on building and operational standards via accreditation.
- 24/24 model of care in facilities which attract capital funding; and
- Bed based unit cost funding based upon a population benchmark.
- The system offers services in facilities that can have as few as twenty beds and as many as hundreds of beds
- Offers facility based and in-home respite care across the entire system
- Is universally available in towns and cities across the nation
- Delivers intensive in-home support packages and low level in-home care across all regions
- Never uses the word "Institution" to describe its residential services
- Is transportable across state borders

The state based disability system provides facility based accommodation in as few as 15,000 beds Nationwide (CSTDA services 2004-05 annual Report 04-05 -AIHW)
It offers:

- "Institutional" (their words not ours) accommodation to just 5,068 persons
- Group home beds to just 10,722 persons
- In-home accommodation support to 18,621 persons ( most in the family home)
- Delivers limited community based and community access support
- Minimal group home respite care and in-home respite care
- Has ceased providing group homes in Victoria and puts nothing in its place
- Calls services that have more than 6/7 beds "Institution" and mandates such classification in the Victorian Disability Bill 2006.
- Offers no choices in accommodation options provided by the state
- Requires people to attend day programs so that group homes can be closed weekday hours
- Offers no tenants rights to people who have to pay rent

Please explain how such policy views as these (and emphasised by Mr Rogers at the Melbourne Hearing) should be tolerated for people with disabilities aged less than 65 years old? The perpetuation of the outdated use of the word "institution" to convey the message that anything larger than a group home is an "institution" and therefore unacceptable is illuminating.

For the state to confess that the decision-makers in government have no capacity to deliver a quality service system, which has in place the necessary checks and balances to ensure people of any age are not "institutionalised" is to admit failure, and incapacity to deliver state-managed disability services in the 21st century.

*There is clear age and choices discrimination here and more than enough justification for our call to have the Commonwealth take responsibility for all accommodation, respite and personal care services to all Australians with a dependent disability regardless of age.*

*There are just so many ways to say this; the state-based disability support system:*

- *is age discriminatory,*
- *choice discriminatory,*
- *Hypocritically turns a blind eye to people with disabilities in squalid SRSs of 20-40 beds*
- *Hypocritically turns a blind eye to frail aged parents providing accommodation and support to severely and profoundly disabled relatives*
- *Ignores the plight of distressed families caring for children with challenging needs*
- *Hypocritically promotes community inclusion whilst practicing exclusion.*

## 5. The impact of Workcover Regulations & O/H/S Regulations, upon the caring family. Homes are workplaces for paid workers – families made liable?

We respond to the questions asked at the Victorian Senate hearing, over the issues we raised about the impact of workcover regulations on unpaid family Carers and we thank the Senators for agreeing that this issue needs attention.

The bizarre events which led to a Gippsland Family being sued by the Victorian Workcover Authority as Third Party liable for a paid care workers injury highlight yet again, how the funded disability industry influences negatively on the much larger unpaid family Care cohort of Australia providing care in the family home.

We provide the Senate Committee with a brief overview of the issues of the 'Krupjak case' in order that the matter will receive remedial attention through this inquiry. How the family came to be sued, is both shameful and a very real threat to the ongoing willingness of families to continue in-home care for disabled kin.
Why the Victorian government will not legislate to exempt families from third party liability in such instances is unbelievable. We reproduce a media story on the case as the simplest way to describe the situation as follows:

### Workcover demands $15,000 for bitten carer – Writ dogs family

Herald Sun – 11 June 2005 - Peter Mickelburough - state politics reporter

The parents of two young disabled boys are being sued by WorkCover in a case that could pose a legal threat to thousands receiving in-home care.
WorkCover, which last year posted a $1.2 billion profit, is pursuing a struggling Latrobe alley family of five for $15,000. It claims they are responsible for weekly compensation and medical bills it paid for an injury suffered by a carer employed by a government-funded agency. It alleges the carer had an adverse reaction to a tetanus injection after being bitten by the Krupjak family's pet collie, Chad, in February last year. Lisa Krupjak told the Herald Sun she and her husband, were devastated. The WorkCover writ was delivered to their Hazelwood South home last month - 15 months after they say they were assured any costs would be paid the agency's insurance. "My husband and I are living on one income and barely survive as it is," Ms Krupjak said. WorkCover can't expect us to pay out all this money. Life is already very difficult. If we had to pay it, we haven't got it."

Two of their three children, Joshua, 12, and Dylan, 6, suffer a previously unknown condition, with underdeveloped coordination and mental functions that have left both in wheelchairs and subject to uncontrolled epilepsy and asthma. Ms Krupjak fears many other families face similar unknown risks, and called for contracts covering in-home care to protect families and carers.

Gippsland Carers Association president Jean Tops said urgent action was needed to protect families and the elderly from being sued for work accidents. ' I can see the potential for mass panic among families receiving in-home care for disabled kids and, indeed, all dependently disabled persons," she said. Ms Tops said families could refuse home-care services and cease caring for disabled or elderly persons in their homes for fear of being sued. She said it should not have been possible for the Krupjaks to be sued, as employers, not clients, were responsible for providing safe workplaces.

But WorkCover claims the Krupjaks were negligent by failing to provide a safe place to work, failing to properly supervise, control or restrain their dog, and failing to protect the worker from a dog bite. A spokeswoman said the Krupjaks were responsible because it was their dog, but expected their insurers to pay. "We issued a writ against them because we have a right to recover from anyone where there was negligence that caused an accident," she said. She said the Krupjaks had been told WorkCover would use its discretion to withdraw the claim if they were unable to pay.

Ms Krupjak said that after demanding she send a cheque or face court, WorkCover had told her it expected the family's insurers to pay. She said their insurance company was yet to determine if it would cover the claim and said the employer had failed to fulfil its responsibilities. "WorkCover has never assessed the property for risks or safety, nor has either of the agencies," she said. "We were never told to restrain or confine any of our animals, and had no reason to believe anyone would be at risk. If we believed that the dog was capable of this the dog would not reside here, especially in the situation we are in with children unable to defend thernselves." She said she had trouble believing that the dog had bitten the carer, and she had not known Chad to bite or even growl at anyone.

Nationals leader Peter Ryan called on WorkCover Minister John Lenders to immediately ensure no other families are pursued in a similar fashion. "This simply should not be **allowed to happen," he** said. If it is, it sends a terrible message to both carers and families. Mr Ryan said it was not enough for WorkCover simply to drop the claim against the Krupjaks. He said the problem must be fixed by amending the legislation or by a minister's direction to WorkCover...........

[ The Victorian government acted (in October 2002) to amend the WorkCover Legislation to protect Volunteers working for agencies from third party liability, but refused to make similar provision for unpaid family Carers. The amendment overview says in part .. This Act was part of the government's response to problems in the insurance sector and includes provisions to protect volunteers from personal liability" "The provisions seek to strike a reasonable balance between the need to protect volunteers and the interests of those who suffer injury. This balance is achieved by providing that a volunteer cannot be held personally liable to pay compensation for anything done, or not done, in good faith by the volunteer while providing a service within the scope of community work organised by a community organisation......... ]

Months of protest and a refusal to accept that unpaid family Carers were volunteers under the legislation, led to a private members Bill in the Legislative Council. The Bill proposed by the Liberal Party was supported by all opposition members (liberal/national and independent) its aim was to protect families from workcover third party liability for injury of paid care workers in the home, by making the Minister responsible for sanctioning recovery action in all such cases. Council Hansard Transcript (20 July 2005) Bill Second reading Speech is self explanatory:

**ACCIDENT COMPENSATION (FURTHER AMENDMENT) ACT 2005 Second Reading Hon Bill Forward MLC.** I move that this bill be read a second time: The contribution that unpaid, volunteer carers make in our community is virtually immeasurable. Our society could not function as it does without the countless hours of dedicated commitment that they lovingly give, day after day, year after year. Some have been caring for their disabled children for upwards of 50 years. All deserve our thanks and our support. This bill goes a very small way towards easing carer concerns about a recent trend by the Victorian Workcover Authority (VWA) to recover its costs from unpaid carers when an in-home worker is injured while working in their home. There is a vast army of unpaid volunteer carers in Victoria, mostly families, caring for the frail aged, for the mentally ill, for disabled adults and disabled children, and for patients utilising hospital in the home services. They need to be reassured that they are not at personal risk of being sued by the VWA. Virtually every one of these carer families receives some type of in-home care to assist them to look after their family members who need support. Home and Community Care services, the Royal District Nursing Service, and a significant array of not for profit agencies are among the organisations which, often funded by State and Federal governments and local Councils, provide in-home services to those in need. In its recent budget, the Federal Government announced $374 million for older Australians and their carers, specifically to support older Australians to remain living at home and in their community. Further assistance was provided in partnership with the NSW Government, Uniting Care and local disability providers to help older people with disabilities to remain in their local communities, rather than entering residential aged care prematurely. This paradigm, of families caring at home for their own family members, with some support from agencies funded by governments, is now the preferred model of service delivery. With this growth of in-home care comes the emergence of a different kind of workplace; a householder’s private non-business property, be it rented, or owned. According to a Victorian Government report, “Who gets HACC 2002-2003”, over 200,000 Victorians received a service from the HACC program in 2002-03. While some estimates put the number of carer families in Victoria as high as 900,000, the 2003 Australian Bureau of Statistics Disability, Ageing and Carers Survey puts the number of carers at 690,400.

This figure is expected to rise as our population ages in the years ahead. The Victorian Government paper, A Fairer Victoria, states on p 26; “By 2021, the number of Victorians over the age of 70 will increase by 65 per cent. “ A key part of the Victorian Government’s strategy is to provide “...support for people to remain independent and living in their own homes.” The strategy also includes funding for an additional 2000 personal alert alarms to support independent living. Obviously the Victorian Government is committed to assisting people to live at home for as long as they can and want to, and in these circumstances the Government must also ensure that no unforeseen impedients are placed in the way of families and carers. Such an impedient is the over zealous use of Section 138 of the Accident Compensation Act 1985, which enables the VWA to recover damages from a third party. There is a legitimate and logical reason why the Act contains the possibility for third party recoveries under Section 138. The principle of enabling third party recoveries where negligence has occurred must be supported in the interests of providing safe workplaces. But the capacity to sue for third party recoveries must be used judiciously. While it may be appropriate for use where labour hire activities are common, in most cases it will be inappropriate where the “workplace” is a third parties’ home, and the worker is employed by someone else. In these circumstances, the worker is employed and Workcover premiums paid by a service delivery organisation, but the place of actual delivery of the service is the homes of the various clients receiving the service. In recent years the VWA has had a deliberate policy of seeking third party recoveries whenever it possibly can. In a statement on 3July, 2000 the VWA stated, in part: ‘Under the *Accident Compensation Act 1985*, WorkCover can recover compensation and medical costs paid as the result of a workplace injury caused by a negligent third party. Rod Marsden is manager of WorkCover's Recoveries Unit. "There is a set formula to assist in the determination of negligence, but at the end of the day, if we pay compensation, we determine how much, in percentage terms, a third party has been negligent," Mr Marsden said. "For example, if you have been assaulted by a third party - and if that third party was totally negligent - we will ask for 100%, but if someone else also contributed towards the assault, percentages to the overall liability may vary." In 2000/2001, WorkCover has budgeted to recover several million dollars. However, the collection of money is not the ultimate aim.

"It is not just to get the money," said Mr Delaney. "There is a strong deterrence aspect. The money coming in is a bonus, a tangible benefit, but prevention – that's really what it's all about." So, how does it all work? Under section 138 of the *Accident Compensation Act* 1985, WorkCover can take legal action against a third party, be it a person or entity (other than the employer or the injured worker), whose negligence has resulted in a workplace injury. For example, if a contractor left a piece of wood lying on the footpath, causing a travelling salesman to fall over and break his leg, WorkCover could sue the contractor to recover the workers' compensation costs. Some other examples could include: • a delivery driver injured in a third party's premises by a forklift driven without proper care and attention; • a contractor injured on the premises of another employer; • an inherent defect in goods supplied for further manufacturing causing • An explosion resulting in a worker being injured. "We actually recover a lot of our money through companies using labour hire workers. Obviously, if a company is using someone else's employee and negligence results in an injury, that company can be a negligent third party," Mr Marsden said. "And that is really where the prevention message comes in. Most companies would be aware that we can charge them under the Occupational Health and Safety Act for failing to have a safe workplace. "But in addition to this, if your negligence leads to another employer's worker being injured, we can also seek to recover from you the cost of compensation." While most companies are not forced to pay the cost themselves as it is covered by public liability insurance, individuals can be hit hard as they will be paying out of their own pockets........ ........ It is important to note the words: “…**individuals can be hit hard as they will be paying out of their own pockets.**

The Accident Compensation (further amendment) Act 2005 was lost on the casting vote of the government. It is now patently clear that any family who accepts in-home assistance from a paid care worker is potentially liable for third party recovery of any paid workers, injury payments.

The argument used by government that a house-holders liability insurance will cover such costs is a hollow one for all the pensioners, home renters and unit dwellers that do not have house and or contents insurance with liability cover. The governments position also fails to take into account the very clear fact that families caring for adult sons and daughters with dependent disabilities have no legal responsibility for those persons save for the ‘rare instance’ where Plenary Guardianship has been granted to family members.

Clearly this is yet another negative impact upon the future of unpaid family caring in the family home.. The risk now applies to all in-home paid care including the aged care sector as well as disability and foster care systems.

Interested persons can view Victorian WorkCover Regulations by visiting http://www.justice.vic.gov.au
Or read the full Hansard Transcripts of the Bill debate by accessing the government Hansard on the Internet: **www.parliament.vic.gov.au/hansard**

## Evidence that other states are implicated

Just this week we have a further incident reported in the Queensland press that relates an incident where a 34 year old man with a mental illness was shot dead by police in the mothers home and now the Mother is being sued for alleged injury inflicted by the 34 year old man upon the policeman. The report says:

**Cop sues mum of man shot in siege** – Reporter- Daryl Passmore - **Sunday Mail 15th Oct 2006 Page 7**

A mother being sued by a police officer after her mentally ill son was shot dead in a siege says she would rather go to prison than pay up. Laurence Beninca was shot in the chest after eight officers from the Special Emergency Response Team were sent to his home at Buderim on the Sunshine Coast in July 2002.

His mother, Jeanette Beninca, faces a damages claim for more than $300,000 from a policeman who was injured, and his wife. Glenn Bruun had surgery to save a partly severed little finger after being hit with a sword brandished by Beninca. Court documents say the ex-officer still suffers a loss of feeling.

Mrs Beninca says she is “dumbfounded by the action, which will be heard at the Brisbane District Court on November 9, and has vowed to fight. “I would rather go to jail than pay, because it is so unreasonable,” she said yesterday. “He cut his finger while they were killing my son”.

It is understood police were called to the property by Beninca,34, who had been having paranoid episodes. He was armed with a sword when officers entered the house. It is understood that Beninca repeatedly struck the shield Bruun was holding. The officer dropped it before receiving a blow to his hand. Beninca was then shot dead by other officers.

Bruun is seeking $200,000 for pain and suffering, loss of income and superannuation, loss of earning capacity and general damages. His wife Karen is seeking a further $100,000 for pain and suffering, general damages and economic loss…end story.

**Clearly families will not continue to provide shelter and care to disabled relatives for whom they have no legal liability, if such actions as these are continued. Unpaid family care is in extreme jeopardy as a result of law that allows such actions to proceed.**

## 6. The debate about a national catastrophic injury insurance scheme?

We make a brief statement about this matter as it was raised at the Melbourne Hearing and in a number of submissions to the Inquiry. We ask the question, how will a catastrophic injury insurance scheme assist the hundreds of thousands of families who care for children who acquired their ‘catastrophic injury’ as an accident of birth or genetics?

We are of the view that the Australian government should take its example from the Japanese experience where all persons who enter the paid workforce are required to pay into a national disability insurance scheme to ensure that all persons will be cared for by the nation, if and when they acquire a dependency.

**For Australia, it would be a simple matter of increasing the Medicare Levi for a national disability care insurance scheme. This is obviously an easy process as the Commonwealth have already made such regulations for other matters i.e. the Guns Buyback scheme.**

## 7. The myth about disability family advocacy, regional responsibility and inclusion?

We take issue with the Executive Director of Disability Services, DHS Victoria in the misleading evidence about consultation and involvement of unpaid family Carers in planning and advocacy.

We want to make this matter abundantly clear. Mr Rogers claim that families are able to influence policy at the regional level through their regional offices. Gippsland Carers Association regularly participates in meetings with the regional DHS. Regional officers make it quite plain that they are not able to influence policy as they claim that is a DHS Central responsibility in spite of our oft repeated concerns about family input. As late, as last month, the region provided is with a copy of a Draft Disability Industry Plan and the covering letter from the Regional Manager asked that we direct our responses to Head Office. (Copy available on request)

The Department of Human Services Victoria recently released a suite of Documents including a " Caring Relationships Policy" for people with disabilities and their families (as raised by GCA at Hearing) Carer groups obtained a draft copy of this document from the internet in 2005. When we asked the Department why carer groups were not given a chance to contribute to the paper, we were told by the DHS Senior Policy Advisor the following:

Quote: 'The draft discussion paper has been developed as a framework for the Department of Human Services to prompt our thinking and discussion. A very limited number of copies of the draft document have been developed with the intention of a small, targeted consultation in mind.' ' We have invited peak bodies and key stakeholders who represent consumer and carer voices, to comment on the paper, and to attend one of four consultations.' 'These invitations were sent to participants in August, giving them over 6 weeks to respond. We have been working very closely with Carers Victoria throughout this time, and feel confident that they will be seeking comment from the carer community in the development of their response. I am sorry that the documentation was posted without our authorisation on a public website and for any concerns that it has caused you.' Unquote.

The Department indicated that Carers Victoria were involved in the discussions and provided contact details...... As we discussed in our Submission to the Senate Inquiry, these issues are of major importance to disability family support groups across the nation because of the lack of funding for specific disability family advocacy.

We reiterate our argument that the Carer Associations of Australia its state Carer Bodies are funded by the Commonwealth Aged Care Department and not FACSIA. Therefore, Disability Carers were given no opportunity to have input to these spurious Documents that carry on the Victorian theme of refusal to recognise unpaid Carers. Recognising the "caring relationship" is an insult to the position we hold as 93% accommodation and personal care service provider.

The Consultation Paper recently released by FACSIA on 'Enhancing the National Disability Advocacy Program Sept 2006, clearly shows that the Disability Advocacy program does not advocate for families as the following graph from the report shows.

Currently, NDAP funding is distributed to different types of advocacy as follows:

| Type of disability | % of NDAP funding |
|---|---|
| Individual | 58% |
| Self | 6% |
| Citizen | 15% |
| Systemic | 20% |
| **Parent** | **2%** |
| **Family** | **2%** |

The application of a minuscule 4% of disability advocacy funding to parents and families is an insult to the families who provide over 93% of the accommodation and personal care needs of dependent people with disabilities in this nation.

**We recommend that the Commonwealth FACSIA Department address the matter of disability family advocacy funding as a matter of extreme urgency to the preservation of the availability of unpaid disability family Carers.**

## 8. Population Based Benchmark Funding and what it might cost?

As discussed in our Submission and re-iterated at the Melbourne Senate Hearing, we are strongly advocating that any new Disability Funding Agreements must include the introduction of Population-based Benchmark Funding. Nothing else will eliminate discrimination in disability accommodation and support services to persons with dependent disabilities aged less that 65 years.

We said we had a suggested Plan for the implementation of a Benchmark Framework of funding and we pointed out that the decades of neglect had caused an enormous "black Hole" in the system that would take decades to remedy. We maintain that the enormous neglect of decades must not be allowed to stop reasonable government from taking the necessary steps to fix the problems and eliminate discrimination.

We proposed a clear strategy for implementation that would address the critical unmet needs in the first five years of the plan by applying the 'disability benchmark' to the 'potential population only.' Our recommendation is that this strategy would in time led to a full population based benchmark Policy for the future of disability services.

The Senators asked us, if we knew how much our proposed scheme would cost and we indicated that we had a formula for costing the proposal based upon known current cost structures for supported residential accommodation and personal care support services. We provide that information here for consideration and recommendation by the Senate Committee.

As previously stated; in order to consider the scope of the problem we need to know who is likely to need or ask for a disability support service. We discussed the 'potential population' as defined by the CSTDA National Data on services, annual report by the AIHW, which is based upon persons with a severe or profound disability only as defined in Figure 1.(b) as follows:

**Fig 1 (b). (AIHW 2004-2005 CSTDA Table of service users per 1000 of the potential population)**

| **Service group** | NSW | Vic | Qld | WA | SA | Tas | ACT | NT | Total |
|---|---|---|---|---|---|---|---|---|---|
| | **Accommodation support** | | | | | | | | |
| No. of service users | 5,980 | 13,199 | 5,034 | 3,371 | 4,550 | 1,128 | 338 | 212 | 33,787 |
| **Potential population** | **230,833** | **166,114** | **138,657** | **70,560** | **52,368** | **17,355** | **11,245** | **9,842** | **697,124** |
| Service users/1,000 potential population | 25.9 | 79.5 | 36.3 | 47.8 | 86.9 | 65.0 | 30.1 | 19.3 | 48.5 |

**Accommodation support - slight of hand reporting:**

- Overall, more than half (51%) of accommodation, support-service users received support to live in their own or family home – services included attendant care, personal care, and in-home support. Furthermore, more than half 51% of accommodation support users also received community access services.
- 6,472 CSTDA funded service users identified that their informal carer was aged 65+
- Only one third (33%) of accommodation support service users were provided with accommodation in group homes.
- 16% were provided with accommodation support in institutions or hostels.
- Over 14,000 (42%) of the 33,175 accommodation support service users also received community access services such as learning and life skills development, recreation and holiday programs.
- National average costs for accommodation support services are as follows:
  Institutions and hostels: $74,461 per service user, Group homes: $83,098 per service user
  Community based support: $18,883 per service user.

**It is readily apparent from the minimum dataset figures that the CSTDA is a totally failed system in meeting the needs of persons with a severe or profound disability (S&P) and a new system is urgently required.**

A ‘customised’ set of Data from the ABS ‘National Survey of Disability Ageing and Carers 2003, detailing the persons with dependent disabilities who were receiving assistance from a **co-resident parent**, was obtained by carers coalition members. This data is compelling and entirely relevant to the Benchmark funding debate.

**Parents as Co-Resident Carers of severely and Profoundly Disabled persons**

Fig 1A. Customised Data for Australian’s with disabilities living with a co-resident parent – Based upon ABS DAC Survey 2003.

| Persons receiving assistance from a Co-resident parent, by age of person | Profound Core Activity Restriction | Severe Core Activity Restriction | Total Profound and Severe | Total with a reported disability |
|---|---|---|---|---|
| 0-15 year | 74,400 | 77,200 | 151,600 | 198,800 |
| 16-29 years | 20,400 | 33,200 | 53,600 | 112,000 |
| ***30 years and over*** | ***22,400*** | ***33,200*** | ***55,600*** | ***80,400*** |
| **Total 0-30+** | **117,200** | **143,600** | **260,800** | **375,200** |

These national co-resident parent carer estimates, tell us that around **55,600** persons with a severe or profound disability were aged over 30 years in 2003 (now over 33 years) and are living with co-resident caring parents who provide assistance to them. Many of these parents are already aged in their 70’s, 80’s and 90’s.

## Addressing unmet need:

In order to address the longstanding unmet needs pervading the current failed system, we require the introduction of **Population-Based Benchmark Funding** that Legislates to address that unmet need in the first instance and then adopts a benchmark that will be sustainable in the long term and which ‘is seen to be’ eliminating the age-based barriers that pervade the current system.

The scope of the issue of population-based benchmark funding of disability services would seem to be overwhelming if it were to be applied in the same manner as that which currently exists to fund aged care, i.e. 103 places/packages per 1000 of the population aged 70 plus adjusted annually. This allocation is currently as set out in figure2. below:

Fig2. Table 12A.1 Report of Gov Services 2006

| Pop 70+ | % of total population | 103/1000 benchmark for bed places or packages |
|---|---|---|
| 1,892, 800 | 9.3 | 194, 958 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%.

To apply the aged care benchmark to adults aged between 15 and 64 who make up a 67% cohort of the general population we would come up with staggering figures as illustrated in Fig3. using a simple 100/1000 benchmark.

Fig3. Benchmark funding allocation 15 -64 based on ABS – DAC 2003 chart-4430.0

| Pop 15-64 | % of total population (b) | 100/1000 benchmark for bed places/packages |
|---|---|---|
| **13,273,437** | **67** | **1,367,000 places/packages (rounded)** |

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

Are the figures above too staggering to contemplate, well then, we will next apply the severe and profound incidence factor to the under 65’s benchmark as a comparative ratio based on incidence of severe and profound disability.

It is not entirely clear why the aged care benchmark funding allocations start at age 70 and not age 65? As a comparator, we are therefore applying the benchmark ratio to persons with severe or profound disabilities aged 15 – 64. This should not be taken to mean that we don’t believe children with severe or profound disabilities ought not to be included. The adult population is used here for ease of understanding the comparison.

## The Severe &Profound incidence Factor applied to Benchmark funding:

- The over 70 years of age incidence rate of sever/profound population is currently 22.5%.

- The 15-64 years of age incidence of severe/profound is relatively static on 3.9% of the total population.

Comparing the over 70 years of age incidence of sever/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+ population to every 1 unit or care package for the population age range 15-64. **This means that the disability support 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. A simple factor to base ongoing benchmark funding upon.

Figure 4 shows the number of beds/packages to be applied to disability services utilising the 18/1000 benchmark as described above.

Fig4. utilising ABS – DAC 2003 population chart-4430.0

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

Clearly, the funding of such a formula for disability services would require a 'quantum shift' in current policy, planning and commitment. This is clearly, what we are asking government to do. Age discrimination in the provision of disability accommodation and support services must cease, justice demands it!

There has to be a sustainable formula for introducing benchmark funding of disability support services.

- A formula that will address unmet need, and decades of neglect in funding of services!
- A formula that will not break the bank, and will be a catalyst for sustaining disability services and the irreplaceable role of unpaid family caring into the future.

We therefore propose a transitional plan to introduce benchmark funding based upon the **potential population only** as set out in the CSTDA-MDS 03-04. To this, we will apply the above benchmark ratio as a basis for funding growth per year for a period of five years at the nominal benchmark of 18 beds /packages/1000 of the potential population only as a sustainable growth per year proposal as follows:

**Fig.5. Benchmark funding based upon 18/1000 potential population 0-64 CSTDA-MDS 2004**

| Potential Population CSTDA-MDS 03-04 | 18 /1000 benchmark for bed places/packages |
|---|---|
| 687,710 | 12,366 new services per year for five years |

**The increases will be based upon the same or similar ratios to those in aged care. i.e. High care beds/packages 40% - Low care beds/packages 40%; and Community Access packages 20.0%. Each category will provide for facility based and home-based respite as a priority.**

**This population based benchmark funding will increase the number of beds/packages by 61,830 over five years across the nation.**

An increase of 61,830 beds/packages over 5 years will potentially only address the accommodation needs of people with severe or profound disabilities aged over 30 years and living with a co-resident parent carer as shown in Fig 1 (b) above.

There is an urgent need to support distressed families who have waited far too long for alternative accommodation options for loved ones. Applying a five year urgent catch-up will remove most persons from urgent out-of-home supported accommodation waiting lists and provide intensive in-home support to frail aged and highly distressed families.

Thereafter, increased funding for accommodation and support services at a Benchmark rate of 18/1000 of the general population aged less than 65 must be introduced incrementally, along with the above formula of increases until catch-up has occurred.

**There will clearly be a need for substantial capital funding for new and innovative facilities to match the growth rate and reform of disability services into more cost effective models and choices of accommodation and supports than currently exist.**

## Funding the population-based benchmark model at current known expenditures:

National average costs for accommodation support services are as follows:

- Institutions and hostels: $74,461 per service user,
- Group homes: $83,098 per service user
- Community based support: $18,883 per service user.

For the purposes of this exercise, we will assume a rounded Group Home average cost of $83,000 to be the High Care component of the new Model of Benchmark funding. We expect that the use of more sensible models of accommodation will become the norm and that economies of scale will reduce the cost.

The average cost of Community based support at $18,800, is more likely to be realistic in the calculation of CACPs equivalent packages. What is not so clear is how much it is likely too cost for "low care accommodation" as this currently barely exists in disability services.

A benchmark for "low care" should sit somewhere between the upper and lower brackets and will be set at $45,000 for the purposes of this exercise. Clearly, there is a demand for Hostel type accommodation as the numbers of persons inappropriately placed in aged care supported residential services (SRS) demonstrates. The use of diversified options that make hostel living available to disabled people is not only sensible economically, but desirable to many people with disabilities themselves.

For ease of demonstration, we will use a benchmark ratio of 30% high care accommodation, 30% Low care accommodation and 20% community disability packages. Again, these packages will offer facility based and in-home respite as a part of each allocation.

## The national disability benchmark funding formula

Calculations based upon the national benchmark funding ratio of 18/1000 of the population aged 15 – 64 will be used as a starting point, but this should not be construed as meaning we do not believe that children with severe and profound disabilities should be included in the benchmark funding arrangements. We do believe all persons aged 15 – 65 with a severe or profound disability have a right to expect access to such support services as the previous fig 4 showed and repeated here for clarity.

Fig6. ABS – DAC 2003 chart-4430.0 ...... age incidence

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

The actual benchmark figure shown above of 238,914 places and packages is an indicator of the vast unmet needs of the disability sector when compared to the aged care sector.

The comparison is stark – Aged care funding provides over 220,000 beds nationally for somewhat less than 13% of the entire population of the nation.

## The Funding formula

Application of the benchmark funding formula 18/1000 of the whole population aged 15-64 years would be as set out in the chart below using current average costs for high care and community care and assuming a median cost for low care per beds/packages using the group home as the only model universally used at the present time.

Fig (AA)

| 18/1000 benchmark of Pop 15-64 | 30%High Care beds/packages | 30% Low Care Beds/packages | 40% community Support packages | Total Recurrent |
|---|---|---|---|---|
| *238,900 (rounded) | 71,670 units | 71,670 units | 95,560 units | |
| 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** |

Now that you understand the reality of funding accommodation and support to the population of persons with a severe or profound disability due to the decades of neglect, we can look at a proposal for the implementation of benchmark funding to address urgent and high unmet needs and sustainable growth incrementally.

Fig5. showed an option for introducing population based Benchmark funding incrementally based upon 18/1000 of the **"Potential Population"** of persons with a severe or profound disability aged 0-64 as set out in the CSTDA-Minimum Data Set 2003- 2004 (AIHW)

**Fig BB The benchmark as applied to the potential population of S&P persons only**

| National Potential Population CSTDA-MDS 03-04 | 18 /1000 benchmark for bed places/packages |
|---|---|
| 687,710 | 12,366 new services per year for five years |

The cost of this proposal to introduce Benchmark funding incrementally, by applying the benchmark only to the **"potential population"** will address the urgent and high level unmet needs for accommodation, support and respite services whilst arrangements that are more detailed are made for the backlog in disability services to be progressively reduced.

The Commonwealth have more than adequate resources with which to immediately commence the reform of disability services. A fairer Australia will ensure that people with disabilities who are aged less than 65 years will not be discriminated against, because the states have failed in their duty of care.

The cost of this benchmark funding implementation proposal applies the High, Low and Community package funding formula based upon a split of 30% High care beds/packages, 30% Low care beds/packages and 40% community care packages and is as follows at Fig (BB):

**Fig (CC) National accommodation/support packages per year for the First 5 years utilising the interim benchmark funding model of 18/1000 of CSTDA 'potential population' estimates**

| 18/1000 of potential Population 0-64 per year | 30%High Care beds/packages | 30% Low Care Beds/packages | 40% community Support packages | Total Recurrent per year |
|---|---|---|---|---|
| 12,366 | 3,710 | 3,710 | 4,946.4 | |
| High Care $83,000 Per bed/package | $307,930,000 | | | |
| Low Care $45,000 Per bed/package | | $166,950,000 | | |
| Community Care $18,800 per Unit | | | $92,992,320 | **$ 567,872,320** |

*[ The distribution of these packages across the nation will match state/Territory population percentages as far as that is practicable.]*

**For Victoria with 25% of the national population the number of new packages per year for the five year period of catch up will be as follows:**

Fig (EE) New Victorian accommodation/support packages **per year** for the **First 5 years**

| 18/1000 of potential Population 0-64 Victoria | 30%High Care beds/packages | 30% Low Care Beds/packages | 40% community Support packages | Total Recurrent per year |
|---|---|---|---|---|
| 3,091 | 928 units | 928 units | 1,236 units | 3,091 packages |
| High Care $83,000 Per bed/package | $77,024,000 | | | |
| Low Care $45,000 Per bed/package | | $41,760,000 | | |
| Community Care $18,800 per Unit | | | $23,244,320 | **$ 142,028,320** |

The total commitment for recurrent funding for Victoria will reach around $710million by the fifth year, and is a reasonable figure in anyone's language given the decades of neglect. This will go a long way to alleviating the chronic 4 year long urgent accommodation wait lists whilst also providing urgent in-home support and respite for those who still wait.

The benchmark funding-five year implementation proposal (as outlined above) will deliver to Victoria a total of 4,640 high care beds/packages, 4,640 Low care beds/packages and 6,180 community support packages effectively doubling the current level of service provision across the board.
*(The population based benchmark proposal compares favourably with the NSW government 10 year plan 2006 commitment of an additional $1.3billion over 5 years effectively doubling the NSW disability budget)*

A Capital funding Program will also be required to ensure that innovative accommodation models are built to meet urgent demand and to provide for real choices made by disabled persons, including the right to choose not to be compelled to attend a day program because a person's home is closed all day.

There will also be required, a provision for dedicated respite facilities, built to support long suffering families, with at least 4 weeks of respite annually for those who continue to care.

We also express the urgent need for supported residential services to diversify the make and model of accommodation and facility based respite options to introduce choices that mirror those of the rest of the Australian population. We are convinced that this will lead to cost efficiencies not possible in the current system.

Caring families are asking the Commonwealth to apply 'Mutual Obligation' to supporting unpaid family Carers, who contribute so much and receive so little.

We repeat our call for aged discrimination to be ceased and for all citizens with dependent disabilities to be treated equally regardless of age.

We repeat our call for disability families to be provided with a funded advocacy voice at the national, state and regional level as a matter of justice and obligation to the thousands of families who by their selfless giving contribute more $30billion a year to the national economy.

To do less is to sanction continued discrimination and neglect.

Once again, we express our gratitude to the Senate for the opportunity to have the voice of caring families heard. We reiterate our appeal for the Commonwealth to take responsibility for accommodating and caring for all persons with a dependent disability regardless of their ages.