

# THE FIRST REAL ANSWER TO THE CSTDA SERVICES CRISIS -POPULATION BASED BENCHMARK FUNDING -

## **Preamble:**

The Federal Government-managed Aged Care System of accommodation and support services for people aged 65 years and over relies upon a schedule of bench-marked funding increases to ensure that services meet the needs for aged care.

This system is based upon a formula for growth funding, which currently funds service increases that maintain a ratio of 105 operational places and packages per 1000 of the population aged over 70 years (9.3% total pop). The planned ratio will increase to 108 places per 1000 population over 70 years, as part of the Commonwealth aged care strategy.

By stark contrast the Commonwealth, State and Territories Disability Agreement (CSTDA) operated by the states and Territories is without any growth policy at all, relying upon departments to go cap-in-hand to state treasury on an annual pilgrimage, and to the Commonwealth every 5 years, as the CSTDA is renewed. The CSTDA is clearly a failed system with thousands of severely or profoundly disabled people languishing on 'unmet needs' waiting lists that have no remedy, often for scores of years. This system fails because it deals out 'cents' off the budget table for people with disabilities.

Disability affects up to 20% of the entire population with 87% aged less than 65. The incidence of severe or profound disability in this age group is 3.9% of the total or 670,000 children and adults aged 0- 64 years.

## **The CSTDA:**

- Is a continuous 'bun-fight' between the states and the federal government over crumbs off the Budget Table for disability services in a 'feed the chooks mentality' of lack of care or planning for people with dependent disabilities.
- There is no formula as the foundation for providing needs-based service increases and therefore no formula as the foundation for population-based bench-marked funding of services.
- The future of disability services is unrelentingly grim, ageing parent-carers are struggling to cope and there are increasing numbers of persons with dependent disabilities who should be in their own supported accommodation, facing eminent homelessness as parent Carers die.
- Younger parent carers are struggling to cope with increasing severity of disability amongst sons and daughters who may previously have died.
- Increases in disabilities such as autism with behavioural implications together with increasing financial stresses and work demands in the era of the two-income family are placing unpaid caring at extreme risk.

We require an entirely new approach to the funding and provision of disability support services, which recognises the absolute responsibility of government to "Plan, Fund and ensure the Provision of services to persons with dependent disabilities".

## What are Population-Based Benchmarks and how are they achieved?

Population-based benchmarking is a term used to describe the use of population data to establish benchmarks or planning ratios that allow resource provision over time, to be monitored and targets to be set. The benchmark or planning ratios make it explicit that only a proportion of the population will require formal assistance from a government program at any particular point in time.

The use of population data also:

- Promotes equity in resource distribution, including geographic equity;
- Links resource allocation to growth in the target population.

In order to make a considered comparison between the level of services offered by the Commonwealth managed Aged Care service system, which is funding with population benchmarking; and the ad hoc funding of disability services under the CSTDA, we need to clearly understand the differences.

As previously stated, the aged care system is based upon a formula for growth funding, which currently funds service increases that maintain a ratio of 105.8 operational places and packages per 1000 of the population aged over 70 years. The planned ratio will increase to 108 places per 1000 population over 70 years, as part of the Commonwealth aged care strategy.

The aged cohort of 70+ years comprises 9.3% of the total population or **1,892,800** persons. The following table shows the allocation of population benchmarked services in aged care (report of Gov services 2006)

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

Pop 70+ in 2005	% 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

(i) Aged ratio of beds/packages is currently = High care 40.8%, Low care 42.4%, CACP's 16.0%, EACH 0.9%.

(iii) Federal Government funding allocated to aged care services in 05-06 was \$7.1billion

To make the disability care benchmark comparison to aged care it is necessary to understand:

- The total population in the over 65 age groups and the under 65 age groups
- The difference between the potential population and the general population
- The application of severe/profound disability incidence rates % to obtain benchmark ratios
- The number of persons currently receiving a service under the CSTDA
- The number of persons currently receiving a service in aged care

Figure (B) shows the total of the Australian population by age range, the % of the total population applied to each age group, the severe or profound incidence rate and the number of persons in the comparable S&P age groups using or likely to use aged or disability accommodation and support services.

Fig (B) population by age range- % total population and the S&P disability rates

Age Range	Population	% of total pop	% S&P Rate	S&P Persons
0-64	17,176,223	86.7		
<b>15-64</b>	<b>13,273,437</b>	<b>67.0</b>	<b>3.9</b>	<b>517,664</b>
> 65	2,634,876	13.3		
<b>&gt; 70</b>	<b>1,892,800</b>	<b>9.3</b>	<b>22.5</b>	<b>425,880</b>

(i) S&P = Severe and Profound disability (ii) Based upon ABS pop stats 2003 of 19,811,100

It can be clearly seen that although the incidence rate of S&P disability in the 70+ age group (22.5%) is far higher than the incidence rate in the 15-64 age group (3.9%) the vast difference in population numbers means; persons aged 15-64 with a S&P disability 517,664 exceed those aged 70+ years 425,880.

## Understanding Population Based Benchmarking that already exists in Aged Care.

The Federal Government uses population benchmarks to allocate funds in aged care.

- The current allocation aims for 108 packages of services per 1000 of the total population aged 70 years and over.
- This figure equates to 10.8% of the total aged population and is approximately half of the estimate of 22.5% incidence of severe or profound disability in the aged.
- This benchmarking model allocates funding on a formula of around 40% high care beds/ 40% low care beds and 20% community care packages.

### How do we calculate a parity population benchmark Formula for Disability services?

Comparing the over 65 years of age incidence of severe/profound disability of 22.5% with the 15-64 years incidence of severe/profound disability 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.

### By comparing 'apples with apples' we are able to apply a population based benchmark to disability services that ensures parity over both sectors of care services.

The percentage of the population with a severe or profound disability in persons aged 15 to 64 years is 3.9%. By utilising the aged care model of approx half of the S&P incidence rate of the target group, an equitable benchmark of 1.8% of the total population aged 15-64 is achieved. This equation converted to just over 18 beds/ packages per 1000 of the total population aged 15-64.

**This means that the disability services sector population benchmark should be 18/ 1000 of the total population aged 15-64 years as shown in the Fig (c) below:**

Fig (c) . utilising ABS – DAC 2003 population chart-4430.0

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

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

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

[The ratio of beds/packages in the disability formula above should be 30% high care beds/ packages, 30% low care beds/packages and 40% community care packages to reflect the increased need for community care services for the under 64 age group]

The calculations of 18 /1000 disability benchmark above, demonstrates that there should be 238,914 beds/packages in disability services. The disability allocation compares almost equally in volume of services with the 108/1000 beds/packages that currently delivers 204,222 aged beds and packages. **This 'apples with apples' comparison occurs due to the much larger population numbers in the 15-64 age cohort and highlights the gross under funding of disability services.**

### The CSTDA Disability Support System - The Disability Difference:

The Federal, State and Territory governments under the CSTDA Multi-lateral and bi-lateral agreements, which are renewed every five years, jointly fund the disability services system. This agreement is due to be renewed, 1 July 2007.

The total budget allocated to CSTDA funded services in 04-05 was \$3.6billion with the Federal government contributing \$1.0billion of which \$563.7million was transferred to the states for care Services and \$463.3million was for employment services managed by the Australian government.

The mix of services provided by the states and Territories under the CSTDA include accommodation support, community support, community access and respite. The Australian Institute of Health and Welfare (AIHW) publish annual Minimum dataset figures that show state by state and national service provision.

## The difference between General population and Disability 'Potential population'

The AIHW calculates the number of service users based upon a per 1000 ratio of the severe or profound population only. It does this on the basis that persons with a severe or profound disability are the most likely to need or become service users.

**It is very important to remember this; when we look at the number of service users per 1000 of the 'potential population' as measured by AIHW, because we are not then comparing 'apples with apples' in relationship to 'total Population' Benchmarking, which is used to fund aged accommodation services.**

What the AIHW figures do show us is the current level of service provision, which can later be compared to the level of service provision in aged care. The following table shows the number of People with S&P disabilities who were users of state managed CSTDA funded services in 2004-2005 as documented in the CSTDA – Minimum Data-set published by AIHW.

Fig: (d)- CSTA Table 1:2 Users of CSTDA services 2004/05- cfdsd -AIHW-07.

	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Australia
Accommodation Support									
No service users	5,980	13,199	5,034	3,337	4,550	1,128	338	190	33,787
Potential population	233,061	168,354	141,593	71,817	71,817	17,513	11,286	10,011	706,608
Service users/1000 potential population	25.7	78.4	35.6	46.9	86.1	64.4	29.9	19.0	47.8
Community Support									
No service users	19,082	33,521	8,497	16,511	9,832	1,943	2,508	910	92,610
Potential population	233,061	168,354	141,593	71,817	71,817	17,513	11,286	10,011	706,608
Service users/1000 potential population	81.9	199.1	60.0	229.9	186.1	110.9	222.2	90.9	131.1
Community Access									
No service users	6,761	19,540	6,392	4,431	4,863	1,513	374	305	44,166
Potential population	233,061	168,354	141,593	71,817	71,817	17,513	11,286	10,011	706,608
Service users/1000 potential population	29.0	116.1	45.1	61.7	92.5	86.4	33.1	30.5	62.5
Respite									
No service users	4,129	11,150	3,761	2,744	1,470	265	287	182	23,951
Potential population	72,497	52,296	44,140	22,326	16,491	5,488	3,503	3,087	219,848
Service users/1000 potential population	57.0	213.2	85.3	122.9	89.1	48.3	81.9	59.0	108.9

The Senate Report on the funding and operations of the CSTDA (Feb 07) found that 'caring families are suffering a crushing and unreasonable burden' and that 'a substantial increase in funding is required in the next CSTDA' due by 1 July 2007. Close examination of the figures above will clearly show why:

Of the 706,608 Australian's with a S&P disability said to have, or likely to have a need for disability support services, only 33,787 persons had access to an accommodation support service.

Of the 706,608 Australian's with a S&P disability, over half are receiving unpaid support from family members and friends, but only 23,951 families has access to a respite service of any kind. It should be noted that only 11,011 of the respite users had access to facility based respite in the reported year above.

There must be a sustainable formula for introducing benchmark funding to disability support services. It must address unmet need and take into account the decades of neglect. The formula must also be a catalyst for sustaining the irreplaceable role of unpaid family caring into the future.

**All citizens with a dependent disability and the families who care for them have a right to receive equal access to supports and services, which eliminate age and jurisdictional discrimination.**

## Data on Co-resident parent Carers tell the real story:

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 1 (e). 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
<b>30 years and over</b>	<b>22,400</b>	<b>33,200</b>	<b>55,600</b>	<b>80,400</b>
<b>Total 0-30+</b>	<b>117,200</b>	<b>143,600</b>	<b>260,800</b>	<b>375,200</b>

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 34 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.

The disability population estimates used by governments to determine need/unmet need for services are derived from the ABS Survey of Disability, Ageing and Carers and can be equally benchmarked across both sectors because ABS asked the same questions of all age groups to determine estimates, degree of disability, need for assistance, etc. Therefore comparing apples with apples!

## Addressing unmet need in Disability services:

The most recent determination of unmet need for disability services is found in the AIHW publication; 'Current and future demand for specialist disability services June 2007'. This report maintains that future demand for disability services will grow substantially. Based upon projected trends in ageing- the number of persons aged 0-64 years with a S/P disability will increase to 752,100 (an increase of 34,600 or 4.8%) between 2006-2010 (chapter 6). This document also maintains that the level of unmet need for disability services had doubled from around 12,600 in 2002 to 23,800 in 2007 with a caution for a relative standard error of 19 chances in 20 to include the possible range 15,900-31,700 persons.

The above AIHW report sites as other factors to be considered in the increased demand for disability services, these are:

- Increase in prevalence of some long term health conditions particularly related to disability
- Increase in level of need due to ageing of service users and their Carers
- The ongoing trend toward community-based living arrangement for persons with disability
- Decrease in access to some mainstream housing options, particularly public housing and boarding houses
- A projected fall in the ratio of informal Carers to people with disabilities.

In order to address the longstanding unmet needs pervading the current failed disability CSTDA funding system, we require the introduction of a complete overhaul which must include '*Population-Based Benchmark Funding*' that Legislates to address that unmet need.

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 is long overdue. Such a system already exists in aged care services and we need to apply such a system to disability services as a matter of extreme urgency.

## Levels of Service in Disability Care and Aged Care:

It is clear from the previous chart Fig (d) that the number of persons accessing disability specific accommodation and respite care services is miniscule when compared to aged care under current funding arrangements.

The disability service users of accommodation support include persons living in large scale residential services, hostels and group homes as well as in-home support via attendant care. The respite service users include own home, centre based, host family, peer support and other ad hoc respite. In order to make apples with apples comparisons, we will only include the last known users of disability centre based respite care services as these services are comparable to aged care accommodation and support services. However, we point out that the figures used are likely to be over-stated as they refer to service users and not allocated respite beds per sae.

To compare accommodation services 'apples with apples' we have to first convert the service users/1000 of the S&P population (potential population) to services per 1000 of the total population aged 15-64 years. We achieve this by converting the Australian accommodation support service users (33,787 persons) to a percentage of the total population aged 15-64 years as follows:

Total population aged 15-64 from fig(c) was 13,273,437

Total number of accommodation support services Fig(d) was 33,787, which represents just 0.26% of the total population aged 15-64 years, or just under 2.6 beds/packages /1000 of that population.

i.e.

Total population 15-64 in 03-04 was 13,273,437 x 0.26% = 34,510 total beds/packages therefore:-  
0.26% = 2.6 beds/packages /1000 of the total population aged 15-64 years.

The number of persons accessing facility respite services was 11,011 (Table 3.1: users of CSTDA funded services 04-05 AIHW NMDS). This represents less than 0.09% of the target population or 0.9 packages / 1000 of the target population.

**Therefore, the current disability accommodation /support population benchmark is a grand total of 3.5 beds/packages /1000 of the population aged 15-64.**

### What should the Comparative Disability Services Population based Benchmark Deliver?

The Disability population benchmark of 18/1000 of the population aged 15-64 years makes it clear just why there is enormous unmet need for specialist disability services. By looking again at the aged care benchmark we see that the allocation not only has a formula (108/1000 pop 70+, but it also sets the % for High care beds/packages, low care beds/packages and community care packages as shown again in Fig (a)

Fig (a) from page 1... **Aged Care Benchmarking** (AIHW residential aged care in Australia 05-06)

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 are currently : High care beds/packages 40.8% - Low care beds/packages 42.4% - CACP's 16.0% and EACH 0.9%.

**This formula delivered 166,291 operational high/low care beds and 34,547 community care packages in 2006 aged Care.**

Taking into account the greater need for low care beds/packages, and community care packages in disability services, we suggest the ratio be 30% high care beds/packages, 30% low care beds/packages and 40% community care packages as shown again in Fig (e) below:

Fig (c) from page 2. **Disability Care Benchmarking** [utilising ABS – DAC 2003 population chart-4430.0]

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

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

(b) Severe & Profound incidence rate of 3.9%

The shortfall in accommodation support is obvious. The current system shows that just 33,787 persons currently have an accommodation support service of whom 10,772 have a group home bed, 5,071 have a large residential or hostel bed and 2,064 have attendant care, the remainder have in-home support (CSTDA DATA SET 04-05).

## The Disability Benchmark and what it will cost ?

It is now possible to see what a population based benchmark funding formula will look like once applied to disability services in comparative parity with aged care benchmarking as shown in Fig (f) below:.

Fig (f) disability benchmark showing funding estimate based upon current average funding costs

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	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	<b>\$10,970,288,000</b>

National average costs for disability 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).

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 comparison of aged EACH 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.

The current provision of disability accommodation support (33,787 users) is less than 25% of the 143,340 benchmark for High/low care beds/packages, and these disability service users included in-home as well as facility based care. It is clear that the CSTDA has failed. The CSTDA is broken and must be fixed.

The 2004-2005 budget expenditure for CSTDA Disability Services was \$3.6billion of which the states and territories contributed \$2.6billion or 72.1 %. The Commonwealth funded the remainder of \$1billion of which just over half (\$563.7 million was transfer payments to the states and the remainder employment services. [13.8 report on government services 2006]

The comparison between the amount of funding provided for all CSTDA disability service categories and the amount of funding required to achieve benchmark funding comparable to aged care accommodation and support funding is obvious from the Fig (e) above.

- Gross current funding of state/territory managed CSTDA services 04-05 \$ 3.2 billion
- Population based Benchmark funding 18/1000 – for the population 15-64 \$10.9 billion

There is clearly a shortfall of funding by at least 2/3rds or \$7.3 billion on the benchmark required for disability services to reach parity with the level of benchmarked funding provided for aged care. Current Aged care accommodation services funding is estimated to be around \$ 7.7 billion for 2005-06.

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. The quantum shift in government policy will have to take into account the following:

- A new agreement on funding that legislates benchmark funding
- A new agreement on equitable contributions by the commonwealth, states and territories
- The implementation of high diversification in housing models to eliminate discrimination in living choices.
- The investigation of private and for profit providers similar to aged care provision.
- A detailed catch up plan.

Other factors that need to be addressed in this debate are the current lack of choices in accommodation types and models that create discrimination for people with disabilities aged less than 15-64 years. The fundamental right to choose the level of service, model and size of the supported accommodation service preferred is absent from all current jurisdictions delivering disability services.

The aged care contrast is stark with multiple models of service offered from nursing homes, hostels, village living cluster apartments, intentional housing, aged care units to town houses. These options are funded and managed across a spectrum of 'for profit' and 'not for profit' service providers.

Unless and until the state governments address this age discrimination and choices discrimination, the provision of disability supported accommodation will remain expensive, exclusionary and unobtainable. The state of Victoria has taken the extra-ordinary decision to separate housing from support and in so doing has ceased to provide funding for capital works save for a small investment in a housing trust.

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 no longer be discriminated against because the states have failed in their duty of care.

Caring families expect the Commonwealth to take the lead in demanding this radical reform of the way that disability services are delivered. Australian's with dependent disabilities and their caring families have the right to expect their government to treat all citizens with dependent disability and handicap equally, regardless of their age at onset.

Caring Disability families are further discriminated against because they are denied a funded peak support and advocacy service that matches the service funded by the CSTDA for people with disabilities themselves. This discrimination also prevails in the provision of funded carer support peak bodies funded from Aged Care but denied to families caring in the disability sector. This discrimination persists in spite of recommendations to fund disability family advocacy from both the Disability advocacy review and the recommendations of the Senate CSTDA Inquiry.

Caring families currently provide approx 92% of all accommodation and personal care services for people with dependent severe or profound disabilities, we have a right to be heard.

#### **We support the call by the National Carers Coalition:**

1. For the Federal Government to immediately match the present States and Territories expenditure of \$3.2billion on services they administer (an increase of \$2.6billion on the current \$0.6billion Federal contribution).
2. From July 2008 an agreed plan for a national population benchmark for disability services be established; and
3. From July 2009 a yearly \$1:\$1 plan of increased funding be applied until the population based benchmark is achieved in Disability Services.
4. That disability family advocacy be funded by the CSTDA to mirror the level of advocacy service provided to people with disabilities themselves to ensure that caring families are given their rightful place at the negotiating and planning tables of government.

Age discrimination and living options choices discrimination against persons with disabilities aged less than 65 years old must cease in the provision of disability accommodation and support services - justice demands it!

**Caring families call upon all Australian Governments to stop the blame game and act to legislate for a 'FAIR GO' for all caring families. The future of unpaid care is at stake. That means over \$30billion of free care services are at risk.**