



Walk a Mile in My Shoes National Carers Coalition

**Submission to
COAG**

For an urgent review of the

CSTDA

**in delivery of effective Services
to people with disabilities aged 0-65
and their unpaid family carers.**

Dated: November 2005



THE IN-EFFECTIVENESS OF THE CSTDA

“The system would work better under one level of Government”

Preamble:

When the ABC Four Corners documentary on unpaid family carers, *The Hidden Army*, went to air in March 2005 more than 900,000 people viewed this program. As is often the case, this Four Corners program was confronting. It raised difficult issues about how Australian society supports the unpaid family caregivers of people who are disadvantaged by – amongst other things - mental illness, from birth disability, degenerative disorders and dementia.

On September 13 of this year hundreds of people participated in the *Walk A Mile in My Shoes* day across the nation. This day of action evolved out of the on-line discussion which took place after *The Hidden Army*. During this discussion, it was suggested that a pair of old, worn out shoes would be appropriate symbolism for the plight of family caregivers. Carers said; that this symbolic representation needed to come to the attention of policy makers as a way of instigating change to give people better lives. At its heart is the birth of the walkamile.net website and the establishment of a national register of Carers with their personal details such as name, age, years of caring, their dependant's relationship and age and their support needs recorded.

More than 1,400 pairs of worn out shoes were placed on the lawns in Canberra and similar demonstrations occurred in Victoria, South Australia, NSW, QLD and WA where state and regional rallies were held concurrently. The overwhelming view of families supports the WAMMS Log of Claims, which demands a complete review of both the failed CSTDA and community mental health support systems, and calls on the Commonwealth Government to take responsibility for all its citizens and to remedy the disgraceful failed disability services system that exists today.

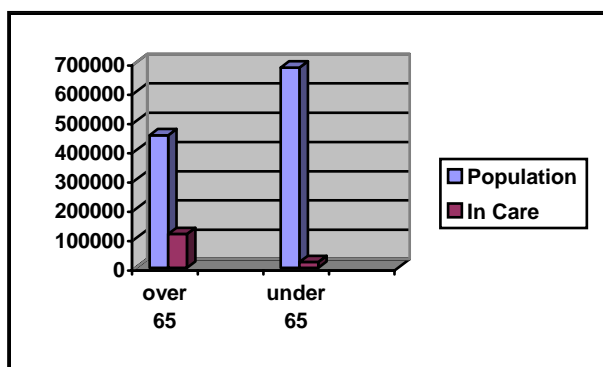
Following the release of the Mental Health Council of Australia Report in October this year, which also called for the Commonwealth to take leadership in the provision of services and support for people with a mental illness, the Federal Health Minister Tony Abbott was quoted as saying “the system would work better under one level of government”.

The Young People In Nursing Homes campaign has also called for such a leadership role from the Federal Government and currently COAG is considering this issue. We reiterate our call for the Commonwealth Government to take responsibility for all citizens with a disability and for their unpaid family carers.

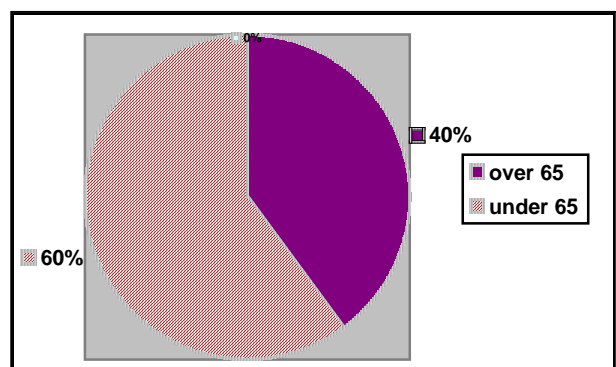
Who and what are we talking about?

The AIHW Disability Support Services report 2000 identifies that there are 655,338 people aged under 65 with a severe/profound core activity restriction. Of this population 2.9% (19,000) lived in some form of supported care outside the family home. This means that 636,338 people with a disability potentially require support to lead their lives. The majority of this support is provided by unpaid family carers and the care families provide, in most cases, spans decades or the life span of their family member.

By comparison, people aged over 65 with a severe/profound core activity restriction totalled 453,200 and of this cohort 25% (113,300) lived in some form of supported care outside the family home (AIHW Australia's Welfare 2001). This means that the potential population in this cohort requiring support in the community totals 339,900. By virtue of age, the requirement for support and assistance to the elderly in the community will be over a much shorter time-frame than that faced by the unpaid family carers providing support in the community to people with a disability aged under 65.



Profound / severe restriction populations by age and number in care accommodation



Severe and profound core activity restriction As percentage of Over 65 and Under 65, age groups

We have identified these two discrete populations based on age in order to identify the potential population requiring support and services and to thus identify potential populations of unpaid family carers. As the diagrams and data identify of the total population with severe/profound core restriction disability 67% of that population is aged under 65. This enables us to use this delineated population base to identify the disparity and inequity that exists in the provision of support and services to people with a disability aged under 65 and their unpaid family Carers.

This is clearly due to the present funding/service delivery arrangements that base access to support and services on the age of the person not the need for support.

Services for people with a disability aged 0- 65 and their family carers.

On the surface people with a disability aged under 65 and their family carers are eligible to receive services through the National Respite for Carers Program (NRCP), the Home and Community Care Program (HACC) and CSTDA funded services. However, the Community Care Review undertaken by the Commonwealth Department of Health and Ageing and the implementation of the resultant '*A New Strategy for Community Care—The Way Forward*' appears to be taking the stance that disability is either a State issue or belongs with the Commonwealth Department of Families and Community services.

The recent initiative of competitive tendering for Programs funded under NRCP has seen a number of respite services, who have successfully provided services to carers of people with a disability aged under 65 years for years, unsuccessful in their tenders for ongoing funding (this is a National trend). Of specific concern is the apparent lack of duplicate/replacement services, albeit under the auspice of a new service provider. Reports indicate that requests for an explanation as to why such services were unsuccessful in their bids to continue to deliver services to the Carers of younger people with disabilities, met with the response that "disability is a State issue".

Further, it is understood that the new auspice organisations all appear to have an aged care focus. It should be noted that when Commonwealth Carer Respite Centres (CRC) came into being in 1996/7 the CRC funding (now part of NRCP) was allocated to *top up* existing HACC providers, covered HACC regions and followed HACC target population guidelines for the provision of services as identified in the HACC Legislation and National Guidelines as follows:

The program shall be directed towards assisting-

- a. *the target population comprising persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the Program, are at risk of premature or inappropriate long term residential care, including-*
 - i. *older people and frail persons with moderate, severe or profound disabilities;*
 - ii. *younger persons, with moderate, severe or profound disabilities; and*
 - iii. *such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister; and*
- b. *the carers of those persons specified in the sub clause (a).*

In a recent report by the Australian National Audit Office (ANAO), "*Helping Carers: the National Respite for Carers Program*", the Respite Centre target group is identified as:

Carers of:

- *people with dementia;*
- *people with dementia and challenging behaviour;*
- *frail older Australians (65 years or over, or 50 and over if Indigenous);*
- *young people (under 65 or under 50 if Indigenous) with moderate, severe or profound disabilities; and*
- *people with a terminal illness in need of palliative care; who are living at home.*

This report also identified that under the NRCP, Respite Services have been established to deliver services to each recipient type of the target group, with:

- 28.1 per cent of services provided to carers of people with dementia;
- 21.9 per cent of services provided to carers of frail aged people;
- 21.6 per cent of services provided to carers of people with dementia and challenging behaviours;
- 21.2 per cent of services provided to people with disabilities; and
- 5.5 per cent of services provided to carers of people receiving palliative care

However, the report also states "*While Health is responsible for services for the aged, including their carers, the Department of Family and Community Services (FaCS) is responsible for services for families with children, people with disabilities and their carers.*"

Family carers of younger people with disabilities are confused by the mixed signals emanating from the National Respite for Carers Program for example:

- *"The Australian Government also supports carers through the National Respite for Carers Program, which allows carers of older people and people with disabilities to have a break to look after their own health and wellbeing, with the comfort of knowing that their dependants are well looked after"* (ANAO Report)
- the recently announced NRCP initiative for Supporting Working Carers guidelines identifying the target group for this Program as Carers of the Aged and Carers of people with Dementia.
- NRCP is funded by Health as part of *Outcome 3: Aged Care and Population Ageing*. **The aim of Outcome 3 is to ensure that high quality, cost-effective care is accessible to frail older people, and their carers are supported**

This perhaps explains the rationale behind the 67% of carers (comprising those caring for someone aged under 65) potentially requiring respite, being allocated only 21% of respite services, whereas the 33% of carers (comprising those caring for someone aged over 65) potentially requiring services receive 76% of services.

A similar aged care focus is identified in the Home and Community Care Program Minimum Data Set 2003-2004 Annual Bulletin where nationally younger people with a disability aged 0-64 comprise only 24.1% of HACC clients, despite being clearly identified and included in the HACC Legislation as a target group.

Throughout this reporting period, respite was provided to 16,274 clients (potential target group numbers 995,238) for a total of 1,594,491 hours, or 97 hours per client per year, or 1.88 hours per client per week. Clients aged 0-64 comprised 11,112 or over 70% of all respite recipients and it needs to be noted that this was the only area of HACC services provided where those aged under 65 were identifiable as the largest service user cohort.

Perhaps this can be explained by the over 65 age group having access to out of home respite and centre based aged care facilities funded/ subsidised by the Commonwealth Government.

These Questions need to be asked:

1. Are people aged under 65 with a disability and their unpaid family carers at imminent risk of being excluded from access to the limited amount of support they presently receive from Programs/services funded through the Commonwealth Department of Health and Ageing?
2. Is Health and Ageing preparing to assign responsibility for younger people with disabilities and their Carers to the Department of Family and Community Services (FaCS) and in doing so ultimately shift the responsibility to the States and Territories?

The 'age' and 'jurisdictional' divide created by the CSTDA has resulted in an extremely unbalanced system of funding and policy directions that have led to massive under-funding of the disability sector.

Benchmark funding in Aged Care, assures a formula for steady growth funding (currently 108 new High/Low care beds/in-home support packages per 1000 of the population aged over 70 – DHA Fact Book 2005). No such benchmark formula exists in Disability funding policies under the Commonwealth State and Territory Disability Agreement,

Nor is it acknowledged that many family carers are providing supports (largely unassisted for decades) to younger people with profound/severe complex disabilities and complex medical / support needs, that would in the Aged Care Sector require specialist Nursing intervention. Aged persons in this category usually access subsidised supported accommodation, or attract individual funding.

The Commonwealth State/Territory Disability Agreement Annual Public Report 2003-04 (August 2005) State by Territory reports, reinforces the claim by families that there is no National standardisation in the way that CSTDA National Policy Priorities are implemented or issues addressed.

Family Carers of younger people with disabilities are becoming increasingly alarmed, angry and frustrated at the level of service being provided to them. They claim that a system of crisis management exists rather than a system of planned and orderly allocation of resources and assistance. They report long or non-existent waiting lists for supported accommodation and inequity in the allocation of resources. Little or no respite care is available for Carers of younger people with disabilities.

Inadequate therapy services and poor interface between disability and aged care services are common with cost shifting between Commonwealth and State programs such as HACC and the National Respite for Carers Program.

Responsibility shifting and blaming between the Commonwealth and States/Territories and age discriminatory practices in guidelines for allocation of resources by governments are commonplace. Over reliance on unpaid family carers to provide support and assistance to younger people with disabilities, and chronic and increasing unmet need in the provision of services to both younger people with disabilities and their family Carers have led to ever increasing levels of family crisis.

Recent data published by the Australian Institute of Health and Welfare on the Commonwealth State and Territory Disability Agreement supports these claims by unpaid family carers of younger people with disability and points to:

- a) a great disparity of service provision and funding per capita between the states and territories, and
- b) an enormous gap between actual service users and the target population.

The following Table indicates the number of service users compared to the potential population of service users and a very large variation across the states and territories in the ratio of service users to potential population within each type of service and between the types of services.

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
Community support									
No. of service users	18,013	28,485	8,564	11,138	9,916	2,173	188	509	78,847
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	78.6	172.3	63.6	161.2	190.3	127.8	16.7	56.6	114.7
Community Access									
No. of service users	6,483	18,441	5,354	10,354	4,827	1,493	419	286	47,636
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	28.3	111.6	39.8	149.9	92.6	87.8	37.3	31.8	69.3
Respite									
No. of service users	4,153	8,607	3,306	2,464	1,390	238	255	155	20,547
<i>Potential population*</i>	<i>71,075</i>	<i>51,205</i>	<i>41,819</i>	<i>21,402</i>	<i>16,211</i>	<i>5,308</i>	<i>3,478</i>	<i>2,761</i>	<i>213,298</i>
Service users/1,000 potential population	58.4	168.1	79.1	115.1	85.7	44.8	73.3	56.1	96.3
Employment									
No. of service users	19,003	18,283	12,036	6,217	5,911	1,667	898	410	64,281
Potential population	108,235	79,161	64,707	34,066	24,789	7,388	6,104	4,379	328,677
Service users/1,000 potential population	175.6	231.0	186.0	182.5	238.5	225.6	147.1	93.6	195.6

* The potential population of respite is the number of people aged less than 65 years, with severe or profound core activity limitation and a primary carer, multiplied by the Indigenous factor for that jurisdiction. Source: Table A1.5, AIHW, 2005

The CSTDA Annual Public Report 2003-04 identifies Nationally that:

- respite services received 6% of the total CSTDA Budget of \$2,650 million – This equals \$185 million.
- 20,547 people accessed respite services. Of those accessing respite 51% (10,479) were aged under 20, 30% (6164) were aged 20-39, 15% (3082) were aged 40-59, and 4% (822) were aged over 60.
- 85% of respite users identified that they had an informal carer. This figure requires investigation as respite is provided in order to assist unpaid carers in their role therefore if the criteria are being met 100% of respite users should identify that they have an informal unpaid carer.
- 6,472 CSTDA funded service users identified that their informal carer was aged 65+
- 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.
- 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

The following table identifies a telling comparison of CSTDA expenditure by the State and Territory governments, highlighting a large variation in spending per capita of potential population across all services. Victoria is the highest spending state at \$5,114, with the Northern Territory and Queensland spending the least at \$2,615 and \$2,609 respectively. NSW, ACT, WA and SA are closest to the average at \$3,854 per capita of potential population.

Table 2: CSTDA expenditure for services other than employment in each state and territory, per capita of the potential population, 2003-04

Victoria	\$5,114
Tasmania	\$4,608
NSW	\$3,843
ACT	\$3,821
WA	\$3,556
SA	\$3,500
NT	\$2,615
Qld	\$2,609
National Average	\$3,854

Source: CSTDA Annual Report 2003-04

Whilst these figures are based on potential population, as distinct from actual services users, this information needs to be considered in the context of expenditure on actual services users and the relatively high proportion of people who are not in receipt of services.

Comparison Funding

Aged Care - Over \$6 billion comprising:

- \$4.7 billion for Residential Care;
- \$1.4 billion for Community Care and Support for Carers, of which \$134.8 million relates to NRCP;
- \$222.3 million for Flexible Aged Care;
- \$59.8 million for Aged Care Assessment;
- \$37.4 million for Ageing Information and Support;
- \$32 million for Aged Care Workforce;
- \$25.6 million for Dementia; and
- \$20.2 million for Culturally Appropriate Aged Care.

CSTDA - \$3.3 billion comprising:

- \$1.638 million Accommodation support
- \$390 million Community Access services
- \$352 million Community Support
- \$301 million Employment
- \$185 million Respite
- \$95 million Other support services
- \$39 million Advocacy, information and print disability
- \$282 million Administrative costs

Unpaid Family Carers of people with a disability aged under 65years

Following the airing of *The Hidden Army* in March 2005 and the *Walk a Mile in My Shoes* day of Action on 13th September 2005 - a national group of carers –The National Carer Coalition - has come into being. This national group has made a commitment to ensure that the September day of action was the first step on the Walk a Mile road to reform and renewal of the support system for people with a dependent disability and their family carers. The group's State Co-ordinators are all giving voluntary services to the coalition and are dedicated to achieving a fairer deal for unpaid family caregivers and those they care for. We argue that the failure by government to adequately support Australian citizens with dependent disabilities impacts severely on both younger people with disability and their unpaid family carers. Families are feeling used and abused by the very system that should be there to support both they and their family members with a disability.

The Walk a Mile National Carers Coalition has produced two Documents titled:

Discussion Paper 1- (s 117) of The Australian Constitution, The Universal Declaration of Human Rights & Australian Citizens with a Disability and their Family Carers" **Discussion Paper 2- "Unpaid Caring - Voluntary or Involuntary Slavery?"** "

We commend them to COAG as vital to further informing this debate and attach copies for your information as part of this submission.

People with Profound and Severe disabilities living with co-resident parent Carers who provide support to them.

The Walk a Mile in My Shoes Liaison Carer group obtained a customised set of Data from the ABS 'National Survey of Disability Ageing and Carers 2003' detailing Victorians and Queenslanders with dependent disabilities who were receiving assistance from a co-resident parent. The following tables show that:

In Victoria there were 93,800 younger people with disability living with a co-resident parent who provided assistance to them. 65,200 persons reported a severe or profound disability. Some 13,900 persons with severe or profound disabilities were aged over 30 years.

ABS Customised Data for Victoria

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	18,600	19,300	37,900	49,700
16-29 years	5,100	8,300	13,400	28,000
30 years and over	5,600	8,300	13,900	20,100
Total 0-30+	29,300	35,900	65,200	93,800

- Core activities are self-care, mobility and communication
- A profound core activity restriction means the person is unable to do, or **always** needs help with, a core activity task.
- A severe core activity restriction means the person **sometimes** needs help with a core activity task.

In Queensland there were 81,800 younger people with disability living with a co-resident parent who provided assistance to them. 53,200 reported a severe or profound disability. Some 5,100 persons with severe or profound disabilities were aged over 30 years.

ABS Customised Data for Queensland

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	14,700	18,500	33,200	43,400
16-29 years	8,000	6,900	14,900	28,100
30 years and over	3,400	1,700	5,100	10,300
Total 0-30+	26,100	27,100	53,200	81,800

- Core activities are self-care, mobility and communication
- A profound core activity restriction means the person is unable to do, or **always** needs help with, a core activity task.
- A severe core activity restriction means the person **sometimes** needs help with a core activity task.

Given that Victoria has 25% of the nation's population and that ABS estimates of disability prevalence vary only marginally from State to State is reasonable to multiply the above figures for Victoria by a factor of 4 to extrapolate the National Data, based on the ABS data results as above.

National Estimates based on above Victorian Data and population base

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

Based on the above figures the CSTDA allocation of \$185.47million nationally for respite would provide the 260,800 family carers supporting a son or daughter with severe/profound disability with \$711:00 worth (approx 24hours) of respite/year compared with the \$11,500 annual upper limit of respite costs per carer under the NRCP as identified in the ANAO report.

The frightening reality of the above national estimates is that around 55,600 persons with a severe or profound disability are currently aged over 30 years and are living with a co-resident parent carer, many of whom are already aged in their 70's, 80's and even 90's.

Co-resident parent carers and their right to access respite

Co-resident family caregivers find it insulting that the latest respite initiative of providing “up to four weeks per year” for parent carers aged 70 or over is touted as an entitlement. Those same carers may have been in the fulltime care role since the birth of their child - for 40, 50, 60 years or more and received little / no assistance or any respite over that period of time deserve far more than this tokenism. What is this – belated Long Service Leave?

As a direct result of governments' refusal to fund and provide 'age appropriate' high care facilities for younger Australians with profound disabilities, over 6,200 young people are now forced to live in aged care nursing homes and many more are supported in the family home by unpaid family carers.

Throughout the nation people aged over 65 years have access to aged care services, including allied health, in every major town and city. These services include housing and supported accommodation options such as nursing homes, hostels, village living, cluster apartments, blocks of flats and purpose built units. Many more Australians, who are neither aged nor a younger person with a disability, choose to live in cluster and village style accommodation, yet options such as these are regarded as “congregated or institutional” living for people with a disability.

So is it ideology or the economic imperative that drives such views? It is suggested that the identified costs of accommodating younger people with a disability in institutions, hostels and group homes ranging between \$74,461 and \$83,098 per year is the greater motivation.

In August 2005, Access Economics released a Report “The Economic Value of Informal Care”. This report quantifies the economic savings generated by unpaid carers and their replacement cost. The report also quantifies the economic/opportunity loss incurred by unpaid family carers in their care/support role. **The replacement cost estimate is currently \$30.2 billion.**

Perhaps the stark reality; that if all 55,600 people with disabilities aged over 30 currently co-residing with ageing parents were accommodated in group homes, the cost would be \$4.6 billion (aged care currently expends \$4.7 billion for residential Care) is also driving policy directions.

As previously identified the population with severe/profound disabilities currently residing outside cared accommodation shows that 67% are aged less than 65 years of age. Where is the equity?

WE ASK THAT COAG TAKE URGENT ACTION TO:

- Abolish the CSTDA and support Federal Government assumption of responsibility for all Australians with disabilities, regardless of their age or...
- Implement an immediate national inquiry into the failure of the CSTDA; with a view to complete reform of state-based discriminatory policies; and...
- Introduce immediate Benchmark funding for disability services which mirrors those currently enjoyed in aged care services provided by the Commonwealth.

WE DEMAND:

- The abolition of 'age discrimination' in supported accommodation choices and access for people with disabilities.
- A fair deal in support services to all families providing an unpaid care service to the national economic good.
- The immediate provision of 'age appropriate' high care facilities to eliminate the practice of placing young adults into aged care facilities.
- an end to Age Discrimination in the delivery of carer support options for those families caring for people with dependent disabilities aged less than 65 years
- An end to the exploitation of unpaid family caregivers as free supported accommodation providers.
- Increased levels of respite and in-home support services to be offered to all full-time primary Carers regardless of the age of the care recipient, including in-home and facility-based respite choices equal to that of aged care services.
- Entitlements to increased financial and material support, entitlement to annual leave in parity with the full time paid workforce, the right to choose to not care, to work in paid employment and to retire from the care role.

Yours sincerely,

Jean L Tops
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Felicity Maddison AM
Queensland/Northern Territory

Nell Brown
New South Wales/ ACT

Volunteer Liaison Carers for Walk a Mile in My Shoes Campaign - seeking a fair deal for caring families

Attach: Discussion Papers 1 and 2- Walk a Mile in My Shoes Campaign.

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