

**Submission**  
**TO**  
**Senate**  
**Community Affairs Committee**  
**Inquiry**  
**into**

**The Funding and Operation of the CSTDA**  
*July 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 - Inquiry into Funding and Operation of the CSTDA**

**Executive Summary**

**On behalf of family Carers of Persons with dependent disabilities**

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

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

Governments are continually looking towards the funded Disability Services Sector and the Funded Disability Advocacy Sector, when seeking to examine the delivery of services to disabled citizens. We believe unpaid family Carers and those for whom they care have the right to be heard at the forefront of planning, the right to expect adequate support in their caring role, the right to choose NOT TO CARE and the right to expect that age appropriate and normative alternate care will be provided to dependent family members.

Our prayerful hope is that a positive outcome for caring families and people with disabilities will be achieved because of this Senate Inquiry. We ask that age discrimination be ceased and that all disabled persons be treated as equal citizens of Australia.

The Commonwealth directly and the States and Territories through the CSTDA fund Disability Advocacy services at the National , State and Regional level for people with disabilities, and that is the right thing to do. The Federal Department of Aged Care also funds Carer Associations at the National and State level for family Carers of the elderly. Some states fund family advocacy for the families of children with a disability up to age 18 years, Victoria being one of these. However, the vast majority of families of adults aged less than 65 years do not have any funded family advocacy at all.

The stakes are high for unpaid caring families who provided 93% of the supported accommodation required by the most dependent of all disabled peoples, the role of disability advocacy must seriously, be questioned and governments must surely answer to why it is that disability family advocacy still has not received funding.

**Families as unpaid carers of persons with disabilities, the CSTDA and unmet needs**

Caring families are the principle providers of accommodation and personal care to disabled people with a severe or profound dependency, shouldering 93% of the total burden without adequate support or recognition. Recently published data from the CSTDA Annual Public Report 2003-04, of all service users, calculates a potential population (those expected to seek a service) of 687,710 persons with a disability. Only 4.9% of these are currently in receipt of a government funded supported accommodation service. Furthermore, just 11.5% of the potential population of persons received any community support.

**The contribution of caring families and mutual obligation**

Putting the contributions of family carers of persons with dependent disabilities into context, is a simple exercise of multiplying the number of persons recognised by the CSTDA minimum dataset as 'potential population' for support services, by the average cost of a group home, Hostel or community support package. The result is a staggering annual contribution of over \$44billion. Access economics puts the figure more conservatively at \$30.5billion. However, you stack it up, it is clear that caring families are owed a massive Mutual Obligation, but receive precious little more than lip service.

The ABS survey of Disability Ageing and Carers 2003 provides us with Customised Data that shows that some 65,300 co-resident parent Carers of Victorian persons with severe and profound disabilities will continue to wait in vain unless major reform of disability services occurs.

### **The National Disaster is just waiting to happen**

Extrapolate the Victorian co-resident parent Carers figure out to the nation level and some 375,200 co-resident parents care for disabled kin and 260,800 have a severe or profound disability. Most significant of these figures are those for parent carers of persons aged over 30 years. For Victoria that is 13,900 persons and Australia 55,600. Forget about all the other figures and you realise that as aged parent Carers die some 55,600 people will face homelessness in a crisis care system that has failed.

Many families caring for disabled loved ones have spent a lifetime in the caring role. Back to before, there were any CSTDA funded services. Back to the days when the only alternative to families caring, was to give up a disabled child to the care of the state. Nothing much has changed since then. Families are still the backbone, the lifeblood of a failed disability support system.

### **Age based discrimination and the Australian constitution**

We believe that Australian citizens who are unpaid family carers and Australian citizens with a dependent disability aged less than 65 years do not enjoy the same citizenship rights as Australian citizens without a disability or those aged 65 years and over because:

Unlike all other Australian citizens, Australian citizens with disability and family carers cannot relocate/move throughout their State/Territory or interstate without being 'penalised' and severely disadvantaged by the loss of essential supports which are bound to the state or region in which someone lives.

If you are a citizen with disability and you are aged over 65 years the Commonwealth have a dedicated supported accommodation and care system that makes nursing homes, hostels and in-home supports, freely available in every major town and city across the nation. These services for the aged have portability across the nation.

The Commonwealth is active in meeting its obligation to the aged citizens within our society, but the states 'do not' do likewise, for people with disabilities or the families who care for them.

It is our strongly held belief that the state based CSTDA system violates a disabled persons Constitutional rights 'to move freely between states and Territories without disadvantage' as protected by Section 117 of the Australian Constitution. We further contend that the state-based disability service system discriminates against disabled persons purely based on their age.

The introduction of the Commonwealth State and Territory Disability Agreements in 1991, gave primary responsibility for the provision of supports to people with a dependent disability aged less than 65 years to States/Territories. The states and territories accepted primary responsibility for the provision of supported accommodation, in-home care, respite, and day services for people with disabilities as defined by the arbitrary age cut-off barrier of 64 years.

### **The Commonwealth Aged Care Difference - Addressing choices in disability accommodation and support.**

The Commonwealth have primary responsibility for the provision of Aged Care services under National Health and Ageing Policy. This includes facility-based aged care accommodation and facility-based aged respite as well as intensive in-home support and respite packages aimed at keeping frail elderly citizens at home for the maximum period. Aged care Nursing Homes, Hostels and village living are freely available to the elderly in every major town and city across the nation.

Blatant discrimination practiced by the states, denies any choice in living options to persons with dependent disabilities. Such discrimination is preventing persons with dependent disabilities from having access to the same or similar choices in supported accommodation options as are freely available to those in the general community and especially to those funded and universally supported in the Aged Care Sector. This denies caring families the right to choose NOT TO CARE due to the non-availability of options outside of the family home.

### **Government policies compound the problems and exploit families**

Deliberate government policies that encourage families to care within the family home at all costs are having a devastating effect upon thousands of families stretch to breaking point. Parents of disabled sons and daughters are coerced into providing a supported accommodation service for a LIFETIME. Families are conditioned to care until they die because most find it impossible to abandon dependent relatives to the scrap heap that is disability services.

### **Family homes are now workplaces**

Other state-based policies such as Workcover for paid workers are causing even greater stress on families by declaring family homes to be workplaces, where any paid help is provided to carers in the home. Workcover Victoria has sued a family as third party liable for a workers injury. Victoria exempts volunteers from this liability, but refuses to exempt family Carers. Clearly, this makes unpaid Carers slave labourers, because they are obviously not volunteers and are not employed by anyone to accommodate or care.

The future of disability services in Victoria 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. Unmet need waiting lists grow ever longer as the state continues the blame game with the Commonwealth over who should pay for services.

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.

### **Recommendations:**

1. Treat all citizens with dependent disabilities equally and stop the blame game between commonwealth and states by having the Commonwealth assume full responsibility for services to persons of all ages who have a dependent disability.
2. Remove all aged based discrimination from accommodation and care support services both out of home and home based.
3. Introduce population based benchmark funding to disability services as an urgent priority utilizing a formula similar to that which currently exists in aged care.
4. Provide funding for disability family advocacy as a matter of urgent priority and, which matches the level of funding provided to disabled persons themselves at the regional; state and National level in order that all decision-makers hear the voice of caring families.
5. Take immediate steps to assist frail aged parent Carers to cope with the burden of care that is destroying their health and speed up the transition of their adult sons and daughters to age appropriate supported living arrangements of their own choices.
6. Provide families caring for disabled persons with the same level of in-home and out-of-home assistance as that provided to Carers of the aged.
7. Introduce national Carer Recognition Policies and protect caring families from Workcover liability where paid help is provided in the family home. The family home is not a workplace.
8. Ensure all full-time caring families have access to at least four weeks of respite care every year as a right not a privilege. This includes the necessity to build dedicated respite care facilities for those with severe and profound dependent disabilities and living with families.
9. Stop the poverty trap for caring families and legislate solutions that give primary caregivers access to paid work.
10. Meet your mutual Obligations to the primary Carers who contribute so much to the nation and receive almost nothing in return.

The family Carers of Gippsland commend our submission to the Senate and would welcome the opportunity to discuss these recommendations with the Community Affairs Committee and the Commonwealth.

End Executive Summary

## **SENATE INQUIRY INTO THE FUNDING AND OPERATION OF THE CSTDA**

### **Preamble:**

The Gippsland Carers Association Inc is a wholly self funded and self managed information, peer support and dedicated family carer organisation, consisting of family and community members providing unpaid accommodation, care and support to persons with a disability, handicap or frailty. The Association is representative of unpaid family Carers of people with disabilities throughout Gippsland, Victoria; however, our influence stretches far beyond the region itself. We are actively involved in networking with caring family groups across our state and nationally as a part of the "Walk a Mile in My Shoes" Carers coalition.

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

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

Because of this neglect, it will be a very difficult task for them to make their submissions to this vital Senate Inquiry. Such neglect will form an integral part of the recommendations for changes proposed to the Senate Community Affairs Committee in their Review of the CSTDA.

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

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

We believe unpaid family Carers and those for whom they care:

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

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

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

## OVERVIEW – THE STAKES ARE HIGH FOR UNPAID CARING FAMILIES.

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

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

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

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

## SUPPORT AND ADVOCACY – WHY NOT ALL CARING FAMILIES HAVE IT?

The Commonwealth directly and the States and Territories through the CSTDA fund Disability Advocacy services at the National, State and Regional level for people with disabilities, and that is the right thing to do. The Federal Department of Aged Care also funds Carer Associations at the National and State level for family Carers of the elderly. Some states fund family advocacy for the families of children with a disability up to age 18 years, Victoria being one of these. However, the vast majority of families of adults aged less than 65 years do not have any funded family advocacy at all.

Population statistics on the incidence of disability, as articulated by the ABS in general population census, make it clear that on a percentage basis the breakdown of population can be literally determined as 20% children aged 0-17 years, 67% adults aged 18-64 years and 13% aged persons aged 65 and over.

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

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

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

Since unpaid family Carers provided 93% of the supported accommodation required by the most dependent of all disabled peoples, the role of disability advocacy must seriously, also be questioned.

## FAMILIES AS UNPAID CARERS OF PERSONS WITH DISABILITIES AND THE CSTDA

To put the contributions of caring families into perspective it is necessary to record that which is glaringly absent from Policy Debate at all levels, that is the very significant role of family in sustaining life for people with dependent disabilities throughout the Australian nation.

*It is not possible to discuss the shortcomings of the CSTDA without first understanding a simple undeniable fact. 'that more than 93% of the supported accommodation and personal care needs of citizens with dependent disabilities is provided by families and friends at little or no cost to government, the tax-payer or the community at large.'*

Considering the caring family in context in Australian disability services, it is necessary to understand their place in the scheme of things. A 'customised' set of Data from the ABS 'National Survey of Disability Ageing and Carers 2003, detailing Victorians with dependent disabilities who were receiving assistance from a co-resident parent, was tabled in the Victorian Legislative Council on 18 May 2005.

This Table shows that in Victoria, there were almost 94,000 disabled persons living with a co-resident parent who provided assistance to them. Some 65,200 of these people reported a severe or profound disability and 13,900 of them were aged over 30 years.

Figure 1: ABS Customised Data for Victorian's with disabilities living with a co-resident parent in 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	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
<b>Total 0-30+</b>	<b>29,300</b>	<b>35,900</b>	<b>65,200</b>	<b>93,800</b>

- 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.

Since it is widely accepted that Victoria has 25% of the national population and the prevalence of disability is generally uniform across jurisdictions, it is possible to put the above figures into the national context with small margins for error noted. The national figure for the incidence of co-resident parent Carers is set out in figure 2 below.

Figure 2: Estimate of ABS Customised Data for Australian's with disabilities living with a co-resident parent - 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
<b>Total 0-30+</b>	<b>117,200</b>	<b>143,600</b>	<b>260,800</b>	<b>375,200</b>

The frightening reality of the above national co-resident parent carer estimates, is that around 55,600 persons with a severe or profound disability were aged over 30 years in 2003 ( would currently be aged over 33 years) and are living with parents, many of whom are already aged in their 70's, 80's and even 90's.

*This disaster of enormous proportions is just waiting to happen as aged parent Carers die leaving severely and profoundly disabled adults to the mercy of a crisis care system that has thus far failed all of them. .*

## UNMET NEED AND THE CSTDA SERVICE SYSTEM IN BROADER NATIONAL CONTEXT

The Australian Bureau of Statistics consistently puts the number of persons with a disability at 20% or 3,9 million of the general population. In 2003 this included 2,556,000 citizens aged less than 65 years. 6.8% or 1,238,600 persons had a severe or profound core limitation meaning they always or sometimes needed assistance with self care. [AIHW Australia's Welfare 2005]

Recently published data from the CSTDA Annual Public Report 2003-04, of all service users, calculates a potential population (those potentially expected to seek a service) of 687,710 persons with a disability. Of these only 33,175 or 4.9% received any accommodation support via CSTDA in 03-04. Furthermore, the report stated that just 11.5% of the potential population of persons received any community support. The following Table indicates the number of service users when compared to the potential population of service users, leaving small doubt that a crisis looms as indicated by those without a service at all.

*Figure 3: Service users per 1,000 'potential' population by service group, for CSTDA funded services by state and territory, 2003-2004. Table also shows the number of persons who did not receive a service in each category of CSTDA responsibility!*

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Accommodation support</b>									
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
<b>Have NO Service</b>	<b>22,743</b>	<b>152,326</b>	<b>129,738</b>	<b>65,939</b>	<b>48,045</b>	<b>15,936</b>	<b>10,914</b>	<b>8774</b>	<b>654535</b>
<b>Community support</b>									
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
Have NO Service	211,170	136,830	126,107	57,936	42,198	14,831	11,060	8,474	608,863
<b>Community Access</b>									
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
Have NO Service	222,700	142,875	129,317	58,720	47,287	15,511	10,829	8,700	640,074
<b>Respite</b>									
No. of service users	4,153	8,607	3,306	2,464	1,390	238	255	155	20,547
Potential population*	71,075	51,205	41,819	21,402	16,211	5,308	3,478	2,761	213,298
Service users/1,000 potential population	58.4	168.1	79.1	115.1	85.7	44.8	73.3	56.1	96.3
Have NO Service	66,922	42,498	38,513	8,916	14,821	5,070	3,223	2,606	192,751
<b>For comparisons the Commonwealth managed Disability Employment Services</b>									
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

### 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.
- 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

## THE CONTRIBUTION OF CARING FAMILIES AND MUTUAL OBLIGATION

The 'mutual obligation' rationale of governments should mean a just reward for unpaid family Carers, but that does not happen. Putting the contributions of family carers of persons with dependent disabilities into context, is a simple exercise of multiplying the number of persons recognised by the CSTDA minimum dataset as 'potential population' for support services i.e. 687,710 persons, by the average cost of a group home accommodation service of \$83,098. (AIHW CSTDA Minimum Dataset 2003-2004)

Fig 4.

Potential population / CSTDA service	Group Home - \$ Cost per bed	Annual potential cost \$
687,710	83,098	57.14billion

If savings of \$57billion is too difficult to contemplate, we can assume that some of the persons in the potential population might be supported in a less costly living option. By taking the average cost of an institution/Hostel bed @ \$74,461, a group home bed @ \$83,098 and a community support package @ \$18,883 multiplied by the potential population, the savings would be likely to be as set out in figure 5:

Fig 5.

Potential population / CSTDA service	Average cost Institution/Hostel/ Group Home/ Community Package - \$ per bed	Annual potential cost \$
687,710	58,814	40.44billion

Numerous reports have analysed the cost savings and contributions of family Carers, the most recent being "The Economic Value of Informal Care" by Access Economics August 2005, which puts the 'opportunity cost of caring' at a very conservative \$30.5billion per annum or 0.6% of GDP or 9.9% of the value of formal health care.

Considering the annual contribution of family caregivers to the national economy, the mutual obligation to families is glaringly, absent from government's response. Lip service is paid to caring families and precious little else.

The families providing 93% of all the accommodation and personal support for persons with dependent disabilities are weary of the rhetoric and are now demanding radical reform of the failed CSTDA system of disability services.

Family Carers expect mutual obligation to mean that the Commonwealth will support families who choose to partner government in caring for disabled citizens.

Caring families expect the Commonwealth of Australia to accept responsibility for all its citizens regardless of their age or disability.

## WAITING LISTS AS AN INDICATOR OF UNMET NEED

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. Carer networks are aware of large numbers of families who have given up in despair over decades of waiting for services that have just not come. Parent carers are in extreme distress and the evidence is clear as the following shows:-

**Confused and heartbroken here I sit.**

*"Two weeks ago I made a decision that for the sake of my personal health and my families' wellbeing I could no longer care for my almost 11 (big boy) year old son due to his ongoing unpredictable aggression, epilepsy and autism due to Tuberous Sclerosis Complex. Naively I thought there would be a group home somewhere for him to have a controlled and structured environment with all of the emotional attachment. Now he is in a respite centre blocking a bed (the second one blocked)WHAT IS GOING ON????*

*I love him soooo much and miss him, I see him every Sunday for lunch. I want the very best for him, I am left with no other choice but to have him foster cared for, this was the only option the Government department gave me that was even remotely close to what I want for him. I asked for a Group Home and they said that there aren't any available, that they are only being maintained. I'm relieved that the respite centre is close by. The ENORMOUS GUILT OF EVERYTHING is almost consuming me. But I know I can't go back now to the way it was for my family"*

## Waiting Lists in Victoria

The state of Victoria, through the Department of Human Services (DHS) does its best to diminish the waiting lists in an effort no doubt, to hide the shame of it all. What is obvious is that the Service Needs Register (SNR) kept by DHS, albeit reluctantly and with a cloud over it's accuracy, shows that there are 4,254 persons currently registered and waiting for supported accommodation and in-home support, of whom 2,207 are rated as URGENT.

Figure 6. (Numbers persons on Victorian SNR- June 30, 2005)

Priority	Shared Supported Accommodation	Day Programs	Home First
Urgent	1085	368	1122
High	637	109	228
Low	1083	30	99
<b>Total</b>	<b>2805</b>	<b>507</b>	<b>1449</b>

The CSTDA minimum data-set (Figure3) clearly shows that just 12,989 persons of the potential population of 165,315 Victorians received an accommodation support service of any kind in 2003-2004. Furthermore, we also know from the Victorian Budget Papers 2004-2005 that only 4,429 persons have a group home or facility-based accommodation bed and 605 persons have a congregate residential accommodation service. The remainder of the accommodation support service group 7,955 are recorded as receiving individual support undefined as to the level of support they receive.

It is clear that the intention of the Victorian Government in reporting to the CSTDA minimum dataset is to inflate the supported accommodation category by including those persons who receive just a few hours a week of drop-in support in the accommodation figures. [Victorian Government Budget Papers – DHS Service Delivery 2004-2005]

The Victorian Budget allocation for all Disability Services in 2003–2004 was a mere \$ 920.81million, with more than half-\$481.5million going to accommodation services for 5,034 clients as listed above, at an average cost of \$96,649 per bed per year. It is obvious that \$439.3million to support the remaining users of CSTDA services is a token amount falling far short of minimum requirements.

### Tender Loving Despair

*Early last year the Melbourne Coroners Court heard the story of Van Nguyen, 74, who hanged himself and his disabled son, Huu-Vui, out of devotion and fear for a child he could not consign to institutional care or to a patchwork of alternative and possibly unsatisfactory arrangements. This dilemma rivals Sophie's Choice with its terrible concessions to a society that observes the platitudes of inclusiveness and disability awareness but has a long way to go before the preaching is practiced widely. With an ageing population and the continuing closing of state institutions, older parents who have dedicated themselves to children damaged through injury or genetic accident have to do much more than tidy their finances and downsize family homes.*

*Barbara Duggan wrote to me in distress at the prospects for her son Lee, now 49, who suffered brain damage at six weeks... "The great and endlessly worrying problem is this: I am 80 and my husband is a very sick man. What then is going to happen to Lee when we can no longer look after him?" ... "this problem is not a popular cause, perhaps since parents of handicapped people are so often ground down by the endless and exhausting work that there is no energy left to insist on adequate care facilities."*

*Leslie Baker's disabled son Ben is now 26. Lesley has canvassed a darker scenario with friends who understand first-hand the despair that floods contemplation of how disabled dependents will survive the parent's decline. "We have a suicide pact," she says. "We'll take the kids with us." "My worst fear is that something will happen to me before I have a chance to settle Ben into anything" she says. "I can't say I've made a final decision but when I look at what is available in Victoria, I can't help but think that when I can't go on perhaps it'll be better to take us both together rather than leave him behind." [Extract The Australian, 21 Aug 2004, by Kate Legge]*

Clearly, some 65,300 co-resident parent Carers of Victorian persons with severe and profound disabilities will continue to wait in vain unless major reform of disability services occurs. Co-resident parents of the 13,900 Victoria citizens with severe and profound disabilities, now aged over 33 years don't have too many years left through which they might see justice, and mutual obligation seen to be done.

Against this background of abject neglect of caring families and their contributions to the welfare of people with disabilities, Gippsland Carers make their submission to the Senate Inquiry in the knowledge that the future of unpaid family caring literally 'hangs in the balance.'

## THE APPROPRIATENESS OR OTHERWISE OF THE CURRENT CSTDA IN MEETING THE NEEDS OF PEOPLE WITH DISABILITIES AND THE FAMILIES WHO CARE FOR THEM

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

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

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

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

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

### **Carers struggle without a break** *extract from article The Age- September 19, 2005*

*"Recent criminal cases expose the plight of those who devote their lives to looking after loved ones. But only those entirely lacking in compassion could disregard the context of (the Carers) actions, just as only the most heartless could remain untouched by the tragic unravelling of Daniela Dawes, a Sydney mother given a five-year good behaviour bond last year for killing her 10-year-old autistic son. One legacy of the policy of deinstitutionalisation is the ever-growing number of Australians now facing a lifetime of caring for elderly parents, or sick or disabled children. Most do so gladly - and the principle of caring for societies vulnerable within the community is undoubtedly sound - but the problem remains that the closing of institutions was never backed by sufficient funds to give carers the respite and long-term support they need."*

*"Disability advocates say many carers are forced to exaggerate a sense of crisis in order to access services, although even this is no magic fix. For the past few years, thousands of Victorians have been on an urgent waiting list for special accommodation, home-help and respite services, and alarming figures show levels of unmet need will continue to soar. The shortage of nursing home beds is another national saga. The grim statistics are a perennial news story, along with the buck-passing between federal and state governments in response. Thankfully, the frustration of carers rarely boils over into sensational headlines. But the quiet despair of overstretched carers should be enough to make our leaders address their plight more seriously."*

Throughout the 1980's the issues of states and the commonwealth both funding the delivery of disability and aged care services came to be a punching bag for each to blame the other for failures. The inability of either regime to meet the increasing demands for support services by the disability community and by their families became more and more obvious. When all else fails policy-makers re-invent themselves and the CSTDA became the sacred icon of a brave new world of the 1990's.

A recent letter received from the Victorian Minister for Aged Care, acting for the Minister for Community Services, and in response to our request for the state to be involved in this Senate Inquiry, said in part:  
" *The Commonwealth Government's contribution to the CSTDA services in Victoria is approximately 14% of total funds, with Victoria's contribution 86% of total funds*"

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

***"Who is in denial here?"***

*My eldest son (we will call him John) was born a little over 17 years ago. He was six when he was correctly diagnosed as suffering from Prader-Willi Syndrome. In the last 11 years or so, my family have become experts on Prader-Willi. Indeed between us we have, collectively almost 44 years (not including John's own 17 years) experience of this genetic malady. Yet who decides what services John will have access to? Who decides where and how he will be cared for in the long term? Who decides what type of future he will have as a welfare dependant person? Perhaps someone who has, maybe if we're lucky heard of Prader-Willi in a brochure somewhere. Who do you think is the expert judge of John's life chances? But who do you think will make those choices? **Who is in denial here?** I want to paint a short word picture for you. I hope you will get my point.*

*Some time ago, John's violent behaviour meant that it was becoming increasingly dangerous for him to stay in the family home. Physical restraint had become, often, the only way of managing his violence. Oh yes, we had tried the chemical options but they either zonked him out or didn't affect him. So, finally, WE organised a meeting of the various health professionals who would be able, or so we thought, to give us some guidance.*

*We met in their (DHS) offices, over coffee. We chatted, but as many of you know, both from within the professional ranks and those of you who are now "customers", the chat was not really getting the results we had come to find. So, I finally said, and I'll never forget this moment. It will haunt me to my grave. I said, well if you don't find some form of accommodation for John my partner and his siblings will have to move out. It's too dangerous for them to stay. A momentary silence fell over the room. I saw a change come over the face of one professional and she said. So, you're telling us that John's siblings are in danger. I felt like saying - No, I'm telling you the moon is made of green cheese!! - Well, in that case, she informed us, they could be removed by court order if we weren't able to ensure their safety. If you can't guarantee their safety, then they could be removed. **Who is denial here?***

It would be wrong to say that the services for people with disabilities have not been improved or increased at all. However, it is just as wrong to say that many people are better off since the introduction of the CSTDA, and it is wrong to say that the system is a success, when clearly it is not.

No-one can deny the plain fact that over 93% of the accommodation, personal care and support needs of Australians with dependent disabilities aged less than 65 years is still today provided by caring families. The data is irrefutable. The CSTDA has failed caring families and those for whom they care.

**As a nation, we must not allow this to continue, it is discriminatory and it is unjust.**

## **CITIZENSHIP AND AGED BASED SERVICE DELIVERY**

Australians with dependent disabilities are Australian citizens who require assistance and support with the activities of daily living. It is generally accepted, that in order for Australian's with dependent disabilities to pursue an equality of life as an Australian citizen, on par with citizens with no dependent disability, they require the support of another person.

It is not accepted that those supports be based almost entirely upon the caring and giving nature of the natural family at the expense of all normal family life. Nor is it accepted that services to people with disabilities be based purely upon the age that a citizen acquires the disability, but such is now the case.

## AGE BASED DISCRIMINATION AND THE AUSTRALIAN CONSTITUTION

There can be no doubting that Australia is a lucky country, but, it is clearly 'more lucky' for some than it is for others.

Our founding fathers would turn in their graves if they could witness the discrimination that pervades our system for meeting the supported accommodation and care needs of Australians with dependent disabilities and frailty! Our founding fathers knew that they should legislate to ensure citizens received equal treatment across state and territory boundaries.

To understand the aged based discrimination of disabled citizens as a critical issue, it is necessary to look at the Australian Constitution and in particular, Section 117, which states:

*"A subject of the Queen, resident in any State, shall not be subject in any other State to any disability or discrimination which would not be equally applicable to him if he were a subject of the Queen resident in such other State."*

*[ Note1: The Australian Constitution passed as part of a British Act of Parliament in 1900 and took effect on 1<sup>st</sup> January 1901]*

*[Note 2: The wording in S117, has not been amended since its acceptance by voting Australians in 1901]*

*[[Note3: The Australian Constitution contains NO Bill of Rights for its citizens ]*

*[Note4: Since the Second World War the Commonwealth Government solely imposes and collects income tax]*

**We believe that Australian citizens who are unpaid family carers and Australian citizens with a dependent disability aged less than 65 years do not enjoy the same citizenship rights as Australian citizens without a disability or those aged 65 years and over because:**

- Resource allocation via the CSTDA is nationally inconsistent and varies from State to State to Territory.
- There is no portability of service, which means that recipients lucky enough to obtain some support in one region cannot move to an adjoining region or they will lose all the support they previously had.
- Lack of portability of services also applies to individual funding where State/Territory borders form the cut out point.
- Unlike all other Australian citizens, Australian citizens with disability and family carers, cannot relocate/move throughout their State/Territory or interstate without being 'penalised' and severely disadvantaged by the loss of essential supports.
- These arbitrary state/territory regulations are in vivid contrast to the national aged care system, which does allow families to move interstate. Families can request a bed transfer for an elderly relative domiciled in an aged care facility and expect the request to be approved.

The introduction of the Commonwealth State and Territory Disability Agreements in 1991, gave primary responsibility for the provision of supports to people with a dependent disability aged less than 65 years to States/Territories. The states and territories accepted primary responsibility for the provision of supported accommodation, in-home care, respite and day services for people with disabilities as defined by the arbitrary age cut-off barrier of 64 years.

The Commonwealth retained primary responsibility for the administration of disability employment services and primary responsibility for the provision of Aged Care services under National Health and Ageing Policy. This includes facility-based aged care accommodation and facility-based aged respite as well as intensive in-home support and respite packages aimed at keeping frail elderly citizens at home for the maximum period.

*All citizens must receive equality across state borders under Section 117 of the Australian Constitution, therefore the CSTDA must cease. - This is aged based Discrimination and it must be stopped.*

## THE COMMONWEALTH AGED CARE DIFFERENCES

If you are a citizen with disability and you are aged over 65 years the Commonwealth have a dedicated supported accommodation and care system that makes nursing homes, hostels and in-home supports, freely available in every major town and city across the nation.

[The ABS statistics on population age prevalence put the number of citizens aged 65 and over at 2.6million or 13% of the total population, with an estimated core activity restriction rate of 17% for males and 27% for females in the age group- AIHW Australia's Welfare 2005 ]

In Dec 2005, the then Federal Minister for aged care announced that: *Aged Care services will be increased by almost 11,000 new places, bringing to 228,000 the total number of government-allocated places following the 2005 Approvals Round. The use of places and packages by older people reflects the growth patterns in their provision discussed above.*

**The significance of the Commonwealth Model of 'aged care service provision is that it is universally available to all elderly Australian citizens once assessed as eligible, with limited waiting times and full transportability across the nation.**

There is a clear case of 'age discrimination' forced upon society by the aged-based division of services between the states and Territories and the Commonwealth. The Commonwealth is active in meeting its obligation to the aged citizens within our society, but the states 'do not' do likewise, for people with disabilities or the families who care for them.

We urge the Commonwealth to:-

- (a) stop age discrimination in the provision of disability support services to Australian citizens.
- (b) Stop the blame game between the states and territories and the Commonwealth by taking responsibility for the provision of accommodation and support services for all citizens with a dependent disabilities regardless of their age.

## ADDRESSING CHOICES IN DISABILITY ACCOMMODATION AND SUPPORT.

The dogmatic regulation of disability accommodation services from the early 1980's when the closure of large scale congregate settings commenced, has meant people with disabilities have had but a single choice in supported accommodation, the group home.

In the 21<sup>st</sup> century, even the group home has lost favour with the Victorian government. The imposition of yet another one-size-fits-all system of service now asks the disabled person (or their Family) to find their own bricks and mortar after which, they may apply for a support service.

This blatant discrimination denies any choice in living options to persons with dependent disabilities and denies caring families the right to choose NOT TO CARE due to the non-availability of options outside of the family home.

The states blatantly discriminate by preventing persons with dependent disabilities from having access to the same or similar choices in supported accommodation options as are freely available to those in the general community and especially those funded and universally supported in the Aged Care Sector. This applies in particular to the state government's refusal to accept nursing levels of residential care, hostels, cluster apartments and village living, all of which are readily available to persons 65 and over.

It is not rocket science, if a living choice is available to other citizens, it must also be available to people with disabilities. What makes a bad service or a so called 'institutional' service is never the 'size of the roof' but the failure of the system of CARE provided.

## THE ABSENT ROLE OF CARING FAMILIES IN PLANNING

It is a shameful reality that the role of families in supporting persons with dependent disabilities is glaringly absent from any, and all planning by those charged with this responsibility under the CSTDA. The state Government through its architects are roundly condemned for their '*minority plans*' which grossly discriminates against the majority, putting responsibility to PLAN, FUND AND PROVIDE for those least able to provide for themselves (as stated above) to the four winds and at the mercy of charity and community goodwill. The shame is in the public arena, but still there is no remedy!

## GOVERNMENT POLICIES COMPOUND THE PROBLEMS AND EXPLOIT FAMILIES

Deliberate government policies that encourage families to care within the family home at all costs are having a devastating effect upon thousands of families stretch to breaking point. The greatest impact of these policies is felt upon full-time unpaid caring parents of adult children, and the parents of profoundly disabled minor children.

The Commonwealth lead in encouraging frail elderly people to remain in their own homes for as long as possible 'because this is what they want' is commendable. Where the intensive in-home supports are put in place to allow this to happen for aged couples (who of course would choose to stay together if possible) is applauded. In making comparisons between keeping frail elderly people in their 'own homes' with the state-based policy of supporting disabled persons in their own homes the difference is stark. For the 93% of persons with dependent disabilities who are living with a co-resident "parent carer" the person with a disability is NOT LIVING IN THEIR OWN HOME.... they are living in the parents home!

Parents of disabled sons and daughters are coerced into providing a supported accommodation service for a LIFETIME. Many are destined never to have an empty nest, never to retire, never to have a life that other families take for granted. Euphemism for 'community inclusion' has come to mean 'keep disabled people in the family home at all costs' the exploitation is blatant.

*Families are conditioned to care until they die because most find it impossible to abandon dependent relatives to the scrap heap that is disability services. This is blatant exploitation.*

## FAMILY HOMES ARE NOW WORKPLACES

Workcover policies for paid support workers has led to the greatest indignation of the family home now being treated as a "WORKPLACE" and families are now being sued if a paid worker sustains an injury whilst in the family home: *[The names have been changed from the following true event]*

*My husband and I have three sons Zac 12, Bob 8, Tom 6. Zac and Tom both have physical and intellectual disabilities and attend a Special Developmental School. Life is very difficult dealing with medical problems constantly, funding issues for equipment such as wheelchairs, standing frames, lifting equipment, continence supplies, and funding for in home services including home care, personal care and respite. We currently access personal care, home care, and respite funded by a care provider. These services help provide quality and quantity of life for not only Zac and Tom but for my husband John, Tom and myself.*

*Last year we had a relief carer for a morning shift providing personal care for the boys on leaving the property the carer informed her employer that our Collie dog had nipped her and she had a Tetanus shot just in case!. [She went on workcover as a result of a reaction to the shot.] In (May 2005), over twelve and two months later I received hand delivered documents stating that my husband and I were to be sued by workcover for the sum of \$14560.00 plus \$678.50 for additional costs. Workcover has never assessed the property for risks or safety nor has either of the agencies. We were never told to restrain or confine any of our animals and had no reason to believe anyone would be at risk. Workcover believes we are liable for the fact that the carer had a reaction to the tetanus shot which may have caused an injury in her arm.*

The Victorian Government refused to amend workcover legislation to exempt family Carers from workcover third party liability as they had previously done for volunteers working for NFP groups.

Caring families in Victoria are liable under workcover for paid support workers who assist them to care and their homes are WORKPLACES. How many will be sued before families quit caring altogether?

## POPULATION BASED BENCH MARK FUNDING IS THE FIRST ANSWER

The Federal Government-managed Aged Care System of accommodation and support services for people 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 clear formula for growth funding, which is currently increases of 103 new operational places and packages per 1000 of the population aged over 70 years, per annum. The planned ratio is to be increased to 108 places per 1000 population per year, over the next four years.

By stark contrast the CSTDA operated by the states and Territories is without any growth policy at all, relying upon departments to go cap-in-hand to the treasury on an annual pilgrimage and to the Commonwealth every few years.

- It is a continuous 'bun-fight' between the states and the federal government over crumbs off the Budget Table for disability services.
- 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 in Victoria 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, and increasing financial stresses and work demands in the era of the two-income family.

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.

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 fund increased services at a rate of 3% of the Potential population of persons with a severe or profound disability aged 0-64 years as urgent growth funding, in the first year of implementation and;
- an increase of 2% of the Potential population in the second year of urgent funding and;
- Thereafter, increased funding for accommodation and support services at a Benchmark rate of 1% of the potential population of persons with a severe or profound disability.

We recommend that the formula be based substantially upon that used in aged care i.e. 60% of the increased funding to be for supported accommodation bed places, 20% for facility-based and in-home respite services and 20% for increased in-home support packages.

**In Victoria** the CSTDA minimum dataset of Potential Population severe and profound persons is currently 169,000 X 3% = 5070 new operational places and packages per annum. Based upon the Commonwealth aged care provision formula this means:

- 4,056, supported residential accommodation and facility-based respite services and;
  - 1,014, 'support to stay at home' packages- as growth funding in the first year.
- In the second year of operation the number of units will be 3,278 or 2% of the potential population and;
- In the third and subsequent years of operation the number of units will be 1,606 1% or;  
1unit per 1000 of potential population of persons with severe and profound disabilities/year.

Multiply this equation by 4 and you get the general picture for the national benchmark reform package.

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

## Conclusion

There are members within our caring family community who believe the Senate will not take our issues seriously. Many more think that to raise all the issues that matter will create a volume that the Senators will be reluctant to read. Probably both of those arguments have a good deal of merit.

Therefore, we ask that you accept this submission as raising the most critical issues affecting unpaid family Carers of people with disabilities; in order that we can convince the Commonwealth that urgent action and reform of the CSTDA is required.

Our overwhelming belief is that the Commonwealth must take responsibility for all its citizens who have a dependent disability or frailty in order to stop discrimination based purely on the age of the disabled person.

Therefore, our most urgent recommendations are brief and to the heart of the nation's responsibility for its most vulnerable of all citizens' children and adults with a severe or profound dependent disability:

## RECOMMENDATIONS

1. Treat all citizens with dependent disabilities equally and stop the blame game between commonwealth and states by having the Commonwealth assume full responsibility for services to persons of all ages who have a dependent disability.
2. Remove all aged based discrimination from accommodation and care support services both out of home and home based.
3. Introduce population based benchmark funding to disability services as an urgent priority.
4. Provide funding for disability family advocacy as a matter of urgent priority and, which matches the level of funding provided to disabled persons themselves at the regional; state and National level in order that the voice of caring families be heard by all decision-makers.
5. Take immediate steps to assist frail aged parent Carers to cope with the burden of care that is destroying their health and speed up the transition of their adult sons and daughters to age appropriate supported living arrangements of their own choices.
6. Provide families caring for disabled persons with the same level of in-home and out-of-home assistance as that provided to Carers of the aged.
7. Introduce national Carer Recognition Policies and protect caring families from Workcover liability where paid help is provided in the family home. The family home is not a workplace.
8. Ensure all full-time caring families have access to at least four weeks of respite care every year as a right not a privilege. This includes the necessity to build dedicated respite care facilities for those with severe and profound dependent disabilities and living with families.
9. Stop the poverty trap for caring families and legislate solutions that give primary caregivers access to paid work.
10. Meet your mutual Obligations to the primary Carers who contribute so much to the nation and receive almost nothing in return.

The family Carers of Gippsland would welcome the opportunity to discuss these recommendations with the Senate Community Affairs Committee and the Commonwealth.