Marcus Bromley  
Acting Executive Officer  
Family and Community Development Committee  

Dear Marcus,  
We draw your attention to the Erratum printed below and attached for the attention of the Committee.  
We apologise for the errors as indicated... to much pressure to complete before our hearing.  
We ask that the amendments as indicated be made to our submission.  

regards  
Jean L Tops  
President  
Gippsland Carers Association Inc  
PO Box 937, MOE VIC 3825  
Phone: 03 5127 1904  
Mobile: 0402 650 375  

Gippsland Carers Association Inc  

Erratum  
20 October 2008  

Submission  
to  
Victorian Government Family and Community Development Committee  

Inquiry into Supported Accommodation Disability and Mental Illness  

October 2008
Page 11. Figure 1. Victorian Accommodation support services Recipients 2004/05.

Group Home Total Persons should read 4243 not 2970...

Page 11. Figure 2.

Total in receipt of supported accommodation should read 5053 not 3788, and;

% of Total S&P should read 3.7 not 2.8....

We regret any inconvenience to the Committee.

Jean L Tops
President
Gippsland Carers Association Inc
PO Box 937

MOE VIC 3825 image001.emf header.htm Erratum Inquiry Disab-Mental Accomm Vic10-08.doc
Submission
TO
Victorian Government
Family and Community Development Committee

Inquiry into

Supported Accommodation
Disability and Mental Illness
October 2008

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

Address: PO Box 937, MOE 3825

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

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

A critical factor in our submission 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 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.

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

We make our case for urgent reform of accommodation services, based upon the complete failure of the system to meet even the urgent requirements of people with dependent disabilities and their families.

The issues we raise have been repeated again and again and again to Inquiry after Inquiry, to Consultation after Consultation and Review after Review; but, little benefit is evident for people with disabilities or their caring families. We therefore commend our recommendations as Germaine to this Review of Disability and Mental Illness supported accommodation services as follows:

➢ The impacts on families as a consequence of the current provision of supported accommodation:

Since unpaid family Carers provided 93% of the supported accommodation required by the most dependent of all disabled people (those who cannot live without support, and those who cannot speak for themselves) we are angered that we have no say in how services are evolved.

Recommendations:

• That the Victorian Government take immediate action to introduce Carer Recognition and Entitlement Legislation, which formalises our role as providers of disability accommodation services, and;

• That the Victorian Government make funding available for the establishment of a regionally based Disability Family Advocacy Network driven by families, to eliminate discrimination against carers of people with dependent disabilities, and;

• That the Victorian Government remove the ‘crushing and unreasonable burden from caring families’ by fixing the broken disability supported accommodation system immediately.

➢ The standard, range and adequacy of care and accommodation currently available

What is completely clear is that the Government and DHS have a definite agenda to opt out of the provision of housing for people with disabilities and this is a national disgrace. The clear agenda in current policy to separate housing from support crystallises this issue.

Recommendation:

• That the Victorian Government take immediate action to make Disability Supported Accommodation Services, and support to Family Carers a ‘First Order Issue’ for Increased Funding and Radical Policy Reform, and;

• That the Victorian Government take immediate action to Reform Disability Services Policy, and;

• That the Victorian Government Act to plan fund and provide for alternate supported accommodation choices for people with dependent disabilities at risk of homelessness, living with ageing parent carers or on indefinite urgent and high priority waiting lists.

➢ Description of current government funded supported accommodation

The CRU as a model of service has become as institutional as its predecessor, the congregate care model. The principle reason for this is gross under funding compounded by the continuation of a dual government and non government system that is crisis driven, discriminatory and fragmented.
Gippsland Carers Association  AIN A00357487— Breaking the Silence on unpaid Family Caring

Recommendations:

- That the Victorian Government opt-out of direct service provision altogether, and;
- Completely reform disability services to ensure that all mainstream specialist disability accommodation services are delivered by the non-government Not for Profit sector and/or private providers of services, and;
- Ensure that a system of external accreditation, evaluation and monitoring of supported accommodation and other disability services is legislated as a First Order Priority.

➢ The adequacy and appropriateness of care and accommodation provided in various government, private and community facilities because of insufficient places in the current supported accommodation system;

DHS, Disability accommodation Policy is a complete mockery because the very same bureaucracy that demands non provision of any accommodation with more than six beds ‘turns a blind eye’ to the more than 2,000 people with disability, acquired brain injury and mental illness existing in Supported Residential Services that have 20, 30 and up to 100 beds. Younger people living in aged nursing homes and with ageing parents scoff at community inclusion policies.

Recommendation:

- That the Victorian Government provide, Age appropriate nursing level of care facilities and age appropriate supported accommodation services for all persons with dependent disabilities aged over 30 years as a matter of ‘First Order Priority’, and;
- For people with profound disability aged less than 30 years where crisis or family breakdown is evident

➢ The Government’s response to and the methods for measuring unmet accommodation needs and how it can be improved:

The Departmental plan to measure unmet under-met need deliberately excludes any person who does not want supported accommodation immediately. Clever in keeping down demand, but ruthlessly inadequate in planning future needs.

Recommendation:

- The Victorian Government take immediate steps to establish a detailed Disability Accommodation and Support Service Needs Register in order to record accurately the current and future demand for Specialist Disability Services.

➢ Alternate approaches addressing unmet needs in supported accommodation in Victoria;

The clear solution to unmet needs is the introduction of Population Based Benchmark Funding as outlined in this submission and which mirrors that already operating well in Aged Care.

Recommendation:

- That the Victorian Government negotiate a Funding Agreement with the Commonwealth that will ensure the Commonwealth and the State each provide a fair share of the cost of implementing a full and fair Benchmark Funding Model to Disability Services for citizens aged less than 65 years.

➢ The accessibility and appropriateness of supported accommodation for specific groups including rural communities, culturally linguistically diverse communities and indigenous Australians.

The current system of supported accommodation services clearly discriminates against people with dependent disabilities living in Rural and Remote Victoria. Accommodation services (group homes) are few and far between (average 90KM between) and 210 beds for a potential population of 7,500 people. Without carers these would be homeless.

Recommendation

- That the Government act immediately to increase the number of respite facilities available to ensure all primary carer families have access to at least 6 weeks of Respite per year, and;
- That the Victorian Government seek the diversification of service providers including the not-for-profit and for profit sectors to offer a wide range of supported accommodation choices to people with dependent disabilities with all options on the table.
The Process for Managing service quality

We are of the firm opinion that one of the greatest failures of the disability supported accommodation service system stems from the fact that there are no external Monitoring and evaluation process.

Recommendation:
- That the Victorian Government take immediate steps to introduce external and independent agencies for Accreditation, Monitoring, Evaluation and Sanction of all disability service providers to ensure a transparent and safe system of supported accommodation options exists and is maintained.

Disability and Mental Illness

Whilst we have made this submission based upon the needs of people with dependent disabilities and the families who care for them, we make it clear that we hold similar grave concerns for people with dependent mental illness who require access to supported accommodation.

Recommendation:
- That the Victorian Government act to ensure that a system of population based supported accommodation services with access to choices is created for people with mental illness.

A Government, which chooses to ignore the ramification upon our families and those we care for is abrogating its duty of care to our most vulnerable citizens and placing our wellbeing at risk daily.

We ask that the Committee ensure the voice of caring families is heard above the clamour of Service Providers and Disability Self Advocates because we alone are in fact irreplaceable. The state and the nation cannot do without our collective $30.5 BILLION contribution to the nation’s budget bottom line in caring for citizens with dependent disabilities.
OVERVIEW

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

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

A critical factor in the formation of the Association is the lack of commitment of successive governments over time, to ensuring that all families caring for persons with dependent disabilities receive support via their own funded family 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 Victoria and the entire nation.

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

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

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

A very real question to be asked by the Committee is 'how in the world will unpaid family Carers know about this inquiry when they have no funded voice to speak for their vast majority?'

As a consequence of the isolation of caring families and the absence of a funded family advocacy network, Gippsland Carers Association have endeavoured to fill the gap for caring families in this submission process.

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

We believe the grossly inadequate current levels of funding, support and accommodation options for persons with dependent disabilities impacts adversely upon caring families and those cared for, preventing many families from accessing normal lives.

Over recent time Gippsland Carers have made detailed submissions to the Commonwealth Inquiry into funding and operations of the CSTDA 2006, current Inquiries into Better Support for Carers and the Tax Review for Pensioners and Carers, each of which are germane to this Victorian Inquiry and will be drawn on heavily in this submission.
We believe that Family Carers:

- Are citizens with equal rights to legal, financial, social and culturally normative lives free from discrimination, exploitation, isolation and prejudice.

- Have the right to access supports that sustain their ability to be fully participating members of society within the full range of choices available to the general community.

- Are entitled to the utmost respect and full involvement in decision-making, including Policy and program direction and planning.

- Unpaid family Carers have the right to choose NOT TO CARE and the right to expect that age appropriate and normative alternate care will be provided to dependent family members.

The caring families of Gippsland thank the Committee for the rare opportunity to be heard by the decision-makers of our state. We express our deep appreciation for your decision to hold this inquiry into Supported Accommodation for people with disabilities. Our prayerful hope is that positive outcomes for caring families, and those for whom we care, will be achieved.

We intend to make our case for urgent reform of accommodation services, based upon the complete failure of the system to meet even the urgent requirements of people with dependent disabilities and their families. The basics to sustain equality of life with non-disabled Australian citizens and their families are barely existent today.

We make the critical point that the issues we will raise have been repeated again and again to Inquiry after Inquiry, to consultation after consultation and review after review, but families have been effectively excluded to date.

We therefore ask the valid question of this Committee, will you ensure that the Victorian Government will be Doers of Reform and not Sayers of Reform to better accommodate and support people with disabilities and those who care for them?
The Terms of Reference

➢ The impacts on families as a consequence of the current provision of supported accommodation:

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

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

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

There are ‘no’ paid professionals writing this submission to the Committee. Such support to the vast majority of caring families is non-existent. Our repeated requests for the funding of a regionally based Disability Family Advocacy Network are still denied.

We want you to know therefore that our plea for dramatic reform of the failed Caring family support system is straight from the heart of grassroots family caring. Please listen to us.

Impact of the absence of Rights and recognition on Families providing supported accommodation to people with disability.

The absence of any credible recognition of the role and rights of caring families as vital to the welfare and wellbeing of disabled people condemn the Victorian Government, the Commonwealth State and Territories Disability Agreement (CSTDA) and its administrators for shutting families out of the accommodation and support decision-making process.

Current funding and operations of disability supported accommodation services are self serving of senior public employees (the Bureaucracy) and the politicians of our nation. Acting in consort both groups ignore the voice of families clamouring for reform, in order that the bureaucracy may continue to foster their own brand of disability service exclusively, and better continue carer family exploitation and neglect.

Most recent evidence of this exclusivity policy in Victoria can be found in the passage of the Disability Bill 2006, which deliberately excludes any recognition of Carers in direct conflict with the CSTDA Multi-lateral Agreements. It does this blatantly in spite of strong evidence that this action isolates and discriminates against Victorian Family Carers who are indeed the major service provider in this state.

The deliberate exclusion of Carers from the Victorian Disability Bill, was ‘marched’ through parliament by a government in absolute control of both houses of parliament and by a bureaucracy bolstered by its own power and ‘community inclusion’ rhetoric. These actions, opposed by many service providers and certainly by family support networks, were supported by the funded disability self advocacy sector in an open rejection of the largest cohort of service providers, the family Carer.
Since unpaid family Carers provided 93% of the supported accommodation required by the most dependent of all disabled people (those who cannot live without support, and those who cannot speak for themselves) we are angered that we have no say in how services are evolved.

**Recommendation:**
- That the Victorian Government take immediate action to introduce Carer Recognition and Entitlement Legislation, which formalises our role as providers of disability accommodation services.

The role of disability self advocacy in the lives of people with dependent disabilities must be seriously questioned here because nothing substantial has changed in decades of neglect of these people and their right to have access to cared accommodation, which today remains an unsolved policy dilemma and a system in crisis.

It is a sad fact that paid disability self advocates actually opposes the call by families caring for people with dependent disabilities to allow persons with dependent disabilities diverse choices in supported accommodation options. This prevents adults with such disabilities from living lives of their own choosing and makes both carer and cared for, captives in the family home, each without a voice.

As providers of 93% of all cared accommodation, justice demands government gives carers an advocacy voice and their rightful place at the Policy and Planning Table of Government.

**Recommendation:**
- That the Victorian Government make funding available for the establishment of a regionally based Disability Family Advocacy Network driven by families, to eliminate discrimination against carers of people with dependent disabilities.

**The History and impact on Families caring for people with dependent disabilities**

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 four and five 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’, ‘integration’ and person centred planning. This major government policy happened to the detriment of those living with family, who largely became the forgotten people!

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%-90%) have never seen the inside of an ‘institution’ because they have always lived with family and in the community.

To this day, over 93% of caring for severely and profoundly disabled dependent persons takes place in the family home. For 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, these promises have now become folk-law.
Clear evidence that the decision-making by Commonwealth, State and Territory government bureaucracies has failed is the fact that such small numbers of people as those domiciled in congregate care settings at the outset of reform remain an issue to this very day, almost three decades on, and with no end in sight. The evidence of the family care crisis left in the wake of this bad public policy is everywhere.

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

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

Gippsland Carers Association made detailed submissions (alone and in consort with others) to the Senate Inquiry into the Funding and operations of the Commonwealth State and Territory Disability Agreement 2006. The Senate Committee made as its unanimous Primary Recommendation that:

"The Commonwealth and the States provide substantial new funding for the next CSTDA" due for signing 1 July 2007, and;

"That the burden of caring upon families was crushing and unreasonable"

Our submission to the Inquiry included detailed proposals for the introduction of Population Based Benchmark Funding (PBBF) of disability services to mirror the PBBF that has existed in aged care for decades; in order to address the disgraceful shortfall in funding for disability services.

'The Senate CSTDA Final Report, recommended that benchmark funding be introduced'

In spite of the fact that the Rudd Government came to power on a commitment to "end the blame game" and to "introduce population based benchmark funding to disability services" there is no commitment to act now on unmet and under met need for disability supported accommodation services in Victoria or elsewhere. There is no commitment to increase funding to meet the challenge of Population based benchmark funding. Many carers will be broken or dead by the time any meaningful changes occur.

The federal government’s promises that increased funding made available by the previous government would be matched $ for $ by the states is a joke. Blind Freddie can see that the states have used their forward estimates to claim matching dollars 'with no real increase' in capacity as a result.

The real kicker for carers is that the $1.9 billion (loudly proclaimed) over 4 years nation-wide can hardly be called “substantial new funding” when nationally less that 7% of 706,600 people with a dependent severe or profound disability currently have an accommodation support funding package. Only some 15,000 of these people actually have a government funded roof over their heads. (Current and future demand for Disability Services AIHW 2007)

Recommendation:

- That the Victorian Government remove the 'crushing and unreasonable burden from caring families' by fixing the broken disability supported accommodation system immediately.
The Crushing and unreasonable Burden on Carers creates stress and mental illness

The ideologues who propound 'community living and inclusion' have no conscience when it comes to the undeniable fact that people with dependent disabilities and mental illness are not housed in their own homes but in the 'family Home.' This makes a mockery of the terminology of people with disabilities having the 'right' to live in their own homes. This ideological claptrap has adversely affected the Health and Wellbeing of Carer Families everywhere.

As a consequence of deliberate policy and strategy to place the responsibility of accommodation and caring for our most vulnerable citizens squarely and unfairly upon caring families, we now see abundant research making very different claims about family impact of failed supported accommodation policy.

Key findings of a report on the 'Nature and Impact of Caring for Family Members with a Disability in Australia' by the Institute of Family Studies (recently released) say this:

“One of the key issues to emerge from this research is that carers and their families experience high rates of mental health problems. Carers had significantly worse mental health and vitality and higher rates of depression than the general population”

Similar findings were reported by Dr Robert Cummings in -The Wellbeing of Australians – Carer Health and Wellbeing 2007:

- Carers have the lowest collective wellbeing of any group we have yet discovered
- Carers have an average rating on the depression scale that is classified moderate depression
- In the general population the wellbeing of people who are separated or divorced is some 5 points below the normal range. The process of caring depresses this by another 16-19 points.

The result of the pressures on families is clear in the following article from a Melbourne Daily.

### Parents dump disabled kids - Herald Sun Report

DISABLED children are being taken to weekend respite centres and not picked up again as desperate parents reach breaking point. Forty Victorian children are living permanently in short-term accommodation after being relinquished by their families, according to the State Government. The Association of Children with a Disability said it could be as many as 100. A shortage of foster carers and complex disabilities mean it can take years to find these children new homes.

Some families struggle on at home for years waiting for foster homes. Two families in Cheltenham and Bulleen have waited four years for new homes for their children. Mother Anita Fejzulai has asked the Herald Sun to help find a loving foster family for her daughter Emine, 14, who has partial chromosomal trisomy, an intellectual disability and epilepsy.

She has spent the past two years at an interim centre in Coburg, which has been a good, stable base but not a home. "I just want someone who will look after her and love her like I do. She's a lovely girl and a very happy girl," Ms Fejzulai said. "But I'm by myself with no family and friends to help me and I find it very difficult to look after her."

Yoralla manager Marisa Harvey said parents failed to collect their children from respite care "only in extreme cases. . . but it does happen". "There are families who are very stressed and extra resources are needed to support them in terms of better access to respite care and other appropriate support services," she said. "There is a desperate need for committed families to open their homes otherwise these children will remain in supported accommodation for the rest of their lives."

Human Services department spokesman Jennene Rodgers said finding families took time, particularly when children's needs were complex. "We would encourage people to become involved in caring for children with disabilities, it's challenging and rewarding," she said. [Susie O'Brien, social affairs reporter 28 March 2005]

Such pressure upon families is endemic in the current system of supported accommodation and care, which is clearly in crisis due to bad policy and inadequate funding.

**Recommendation:**

- That the Victorian Government take immediate action to make Disability Supported Accommodation Services, and support to Family Carers a 'First Order Issue for Increased Funding and Radical Policy Reform.'
The standard, range and adequacy of care and accommodation currently available

The population statistics show the crisis that exists today:

Population statistics 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% persons aged 65 and over. By far the largest cohort of persons in the population are those aged 18-64 years, with the greatest of those being ‘baby boomers’ on whom the impact of disability is set to escalate catastrophically in the decades to come.

The national capture of persons with a severe or profound disability who are receiving a support service funded by the Victorian government is found in the (CSTDA) Minimum Dataset produced by the AIHW annually. The dataset identifies the potential users of funded supported accommodation services is a conservative 706,600 people or 3.9% of the population aged 15 to 64 years Australia-wide. (Based on (ABS) Survey of Disability Ageing and Carers 2003 (SDAC).

Taking the broad ABS population statistics (above) as our model we can see that Victoria with a population of 5,274,000 (March 2008) will have a minimum of 4,588,400 persons aged under 65 years of whom 178,900 or 3.9% will have a severe or profound disability and some 3,533,000 persons aged 15 to 64 (67%) of whom 137,809 or 3.9% will have a severe or profound disability.

Most recent Minimum CSTDA Minimum Data is published for the year 2004/05.

Fig 1. Victorian Accommodation support services Recipients 2004/05

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large Residential/institution</td>
<td>599</td>
</tr>
<tr>
<td>Small residential/institution</td>
<td>45</td>
</tr>
<tr>
<td>Hostel</td>
<td>166</td>
</tr>
<tr>
<td>Group Home</td>
<td>2,443</td>
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<tr>
<td>Attendant Care/personal care</td>
<td>413</td>
</tr>
<tr>
<td>In-home accommodation support</td>
<td>7594</td>
</tr>
<tr>
<td>Alternate family placement</td>
<td>94</td>
</tr>
<tr>
<td>Other accommodation support</td>
<td>528</td>
</tr>
<tr>
<td>Total Accommodation support</td>
<td>13,199</td>
</tr>
</tbody>
</table>

Fig 2.

| Total severe / profound aged 15-64 - Victoria | 137,809,000 | % of Total S&P |
| Total in receipt of supported accommodation  | $0,538,528  | 28 3.7 |
| Total in receipt of accommodation support    | 8,629       | 6.4 |

Note a: The AIHW Minimum dataset states that some users of CSTDA funded services are persons with a moderate disability, therefore the % S&P user figures are inflated by an estimated 18% overall.

Note b: AIHW estimated the Potential Population of Victorians who may require supported accommodation services in Victoria in 2004/05 to be 168,134 persons based upon the ABS/SDAC 2003.

Note c: It is clear that the total number of persons with a severe or profound disability estimates will have grown as the most recent formal statistical data (ABS_SCAC) is now 5 years old.

The ABS/SDAC 2003 estimates that the number of Victorians with a severe or profound disability aged over 30 years and living with co-resident aging parent carers is 13,900. These persons will all now be over 35 years old. There are “NO” Plans by the Victorian Government to address the issue of impending homelessness for all these citizens when aging parents become too ill to care or die.
A ‘customised’ set of Data from the ABS-SDAC 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.

The following Table shows that in Victoria, there were almost 94,000 disabled persons living with a co-resident parent who provided assistance to them in 2003. Some 65,200 of these people reported a severe or profound disability and 13,900 of them were aged over 30 years.

There is clear evidence of a crisis of major proportions just waiting to happen because ‘no plans’ are in place to meet the need for alternate care for any of these ageing citizens.

**Disability Residential Services- it’s a Government Responsibility unmet!**

It is irrefutable that there have been no additional beds provided in Disability Supported Accommodation services over the past 4 years; and an even more telling figure is the changes in growth patterns since 1999:

<table>
<thead>
<tr>
<th>Type</th>
<th>30 June 1999</th>
<th>30 June 2007</th>
<th>Change</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSA residents</td>
<td>3847</td>
<td>4658</td>
<td>+811</td>
<td></td>
</tr>
<tr>
<td>Training Centre residents</td>
<td>942</td>
<td>430</td>
<td>-512</td>
<td></td>
</tr>
<tr>
<td>Total Residents</td>
<td>4789</td>
<td>5088</td>
<td>+299</td>
<td>+6%</td>
</tr>
<tr>
<td>Cost $million</td>
<td>$281.979</td>
<td>$529.3</td>
<td>+$247.32</td>
<td>+88%</td>
</tr>
<tr>
<td>Average per resident</td>
<td>$58,880</td>
<td>$104,029</td>
<td>$45,149</td>
<td>+77%</td>
</tr>
</tbody>
</table>

Source: 1999 base figures are from VicHansard, Council, Answers to Questions on Notice, No. 533 on 11 June 2003 and 645 on 16 Sept 2003. 2007 figures are from DHS Annual Report 2006-07, p 113

This $247.32 million funding increase accounts for a high proportion of increased funding to disability services since the change of government - and the outcome is a mere 6 per cent increase in capacity in eight years.

As we understand it, the number of residents is actually an annual throughput, rather than the number of beds. DHS does not like to talk in terms of beds of course; this clearly puts the expenditure under too great a spotlight.

These figures also demonstrate the ‘churn’ of people from training centres to SSA. What we will see in the figures for 2007-08 is the churn from residential aged care to SSA, and the completion of the Kew redevelopment.

**What is completely clear is that the Government and DHS have a definite agenda to opt out of the provision of housing for people with disabilities and this is a national disgrace. The clear agenda in current policy to separate housing from support crystallises this issue.**
The Age - State failing to house intellectually disabled - Carol Nader - March 13, 2006

If TY Cuttriss could speak, he would probably utter words of frustration. His mother Yolanda says he has a great desire to communicate verbally. He just can't. He has had an intellectual disability for all his 28 years. Mrs Cuttriss is frustrated, too, that her son has been waiting for appropriate accommodation for 10 years. But there is no place for him. Instead, he lives with his parents, which has put incredible strain on the family. Their plight is not unique. There are some 1370 people with disabilities in Victoria waiting for supported accommodation, according to a report by the Auditor-General tabled in State Parliament yesterday.

"Sometimes you get so fed up and so frustrated with the whole situation that it makes it very difficult," Mrs Cuttriss said. "He's always demanding our attention, and so mentally and physically for us it's very wearing. You expect to care for your children until they're 18, but after that they generally are able to care for themselves. But not so for people with children with a disability."

Auditor-General Des Pearson found the Department of Human Services had taken a "reactive" approach to disability and had failed to provide support for all those requesting it. Demand was rising by 4% to 5% each year but the department had not accurately quantified future needs. "As a consequence, residential service recipients will suffer and the system will continue to be crisis-driven," he said.

The report also raised concerns about the conditions of some houses. The department itself had identified about 200 of its houses as not meeting building or occupational health and safety standards. Work had progressed on upgrading those buildings, but the department has received just $44.6 million of the $123.2 million it needed to bring the houses up to standard.

It said in the past four years, the Government had created 77 new facilities to replace unsuitable ones but had not increased bed capacity. Some houses had an "institutional" mindset that catered for residents' physical needs rather than operating like a home where they were encouraged to develop independence.

It cited instances of incompatibility in shared accommodation that had adverse effects on residents. In one case, a resident had a disorder that meant they were not suited to communal living but there was no option than to live with others. Staff had to manage the resulting conflict. It said positive steps had been taken to tackle some "long-standing system shortcomings", such as establishing a framework to improve quality of support and accommodation.

National Disability Services state manager Kerry Presser, part of the report's reference group, said it proved the system was driven by crisis.

Recommendation:

- That the Victorian Government take immediate action to Reform Disability Services Policy, and;

  Act to plan fund and provide for alternate supported accommodation choices for people with dependent disabilities at risk of homelessness, living with ageing parent carers or on indefinite urgent and high priority waiting lists.

  ➢ Description of current government funded supported accommodation;

The dogmatic departmental 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 bricks and mortar, the group home or community residential unit (CRU).

The CRU as a model of service has become as institutional as its predecessor, the congregate care model. The principle reason for this is that the funding and operation of the CRU model is once again crisis driven and under-funded. This has given rise to a Dinner, Bed and Breakfast group home model where people with disabilities are required to attend an external day activity program Monday through Friday even when they have reached middle aged or retirement age. Most units do not provide day staff except for gazetted holidays.

The single staff person 'sleep-over' policy renders persons with profound dependent disability as liable to physical, mental or sexual abuse as they may have been in the other congregate setting of the past era.

Clients of group homes have little or no say in who they will live with, how their lives will be organised, or how their wellbeing will be assured.
The cramped living conditions in group homes (that pretend to be normal living) is a far cry from the bed-sitter-ensuite regulations that govern accredited and monitored aged care options of the 21st Century.

Today, even the group home has lost favour with the Victorian government because it has failed to deliver on the promise of community inclusion. 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, which they may or may not receive.

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 most senior bureaucracy blatantly discriminate by preventing people 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 age appropriate nursing levels of residential care, appropriate hostels, cluster apartments and even village style living, all of which are readily available to persons aged 65 and over.

We repeat that the Department of Human Services, Victoria, Disability Division clearly practices ‘age discrimination and arbitrary regulation’ to deny choices in disability accommodation options to people with dependent disabilities aged less than 65 years.

This is most apparent in the DHS unwritten policy that: ‘DHS (Government of Victoria) will not fund accommodation that has more than six (6) beds in any one facility’ as this would be institutional! The following case commentary reflects this hypocrisy very clearly:

Gippsland Carers Association was offered the use of a twelve bed accommodation facility (formally utilised for aged care) for use as a desperately needed respite facility for the region.

Each unit was a bed-sitter with ensuite, in two separate wings of six beds. Set in an idealic park location, it would have been perfect as a respite option, but the Victorian Director of Disability Services, then Mr Arthur Rogers, refused to consider the option, why? ‘Because it would be an institution by virtue of the fact that it had twelve (12) beds.’

The facility described above was of approved aged care accreditation standard and far superior in configuration to any group home we have ever witnessed. (GCA Holiday respite proposal 2002)

The Gippsland Region has just 18 designated adult respite beds and families are crying out for holiday length respite options to no avail. It is little wonder that the mental health of carers is so far below the national average!

It is very clear to caring families that the hyperbole that surrounds the current government’s stance on choices in disability accommodation options stem not from the size of the roof being provided, but from the quality of the care delivered, and from the complete absence of any external monitoring or evaluation system for disability accommodation services.

A critical factor in the bureaucratic mis-management of disability accommodation services is that the government department is at the same time; the funding body, direct service provider, policy-maker and internal evaluator of these services. Unless and until the disability accommodation system is radically changed, the extreme crisis management of these services will continue.
Recommendations:

- That the Victorian Government opt-out of direct service provision altogether, and;

  Completely reform disability services to ensure that all mainstream specialist disability accommodation services are delivered by the non-government Not for Profit sector and/or private providers of services, and;

  Ensure that a system of external accreditation, evaluation and monitoring of supported accommodation and other disability services is legislated as a First Order Priority.

- The adequacy and appropriateness of care and accommodation provided in various government, private and community facilities because of insufficient places in the current supported accommodation system;

People with disabilities in Supported Residential Services (SRS)

The Departments Disability accommodation Policy is made a complete mockery by the clear fact that the very same bureaucracy that demands non provision of any accommodation with more than six beds *turns a blind eye* to the more than 2,000 people with disability, acquired brain injury and mental illness who eek out an existence in Supported Residential Services that have 20, 30 and up to 100 beds. (Community Visitors Annual Report 2005).

The SRS Community Visitors Report states that:

"As at June 2005, there were a total of 203(SRS) facilities with 6,796 registered beds. Of these beds, 2,399 were occupied by people paying pension level rates." Furthermore, the Community Visitors report states that:

"The 2003 SRS census (TQA Research 2004) states that 45% of residents in pension-level SRSs have a psychiatric disability, 14% have an intellectual disability, 8% have acquired brain injury and 2% have serious medical issues."

The above damning statistics on people with disabilities in sub standard ‘institutional’ accommodation and care services is evidence of the blatant double standard that is ‘accepted disability accommodation policy’. Our Victorian elected representatives have an absolute obligation to denounce such double standards and eliminate them.

People with Disabilities in Aged Care Facilities:

It is grossly hypocritical to discriminate against people with disabilities who need supported accommodation, purely on the basis of their age. This is clearly what happens in the arbitrary divide of Aged Care accommodation services and Disability accommodation services.

It is wrong to say to a person with a disability aged 60, you cannot have access to Hostels, village living, nursing levels of care, clusters of units etc, but then say to the person aged 65, ‘yes you can have access to these living options’.

This is Age Discrimination, but no-one is doing a single thing about it because it suits the system to put these restrictions upon people with disabilities aged less than less that 65 years and upon their increasingly distraught and angry families.

In spite of the COAG agreements to move some 2000 Victorians with severe and profound disabilities from quote: inappropriate placement in aged care unquote: the snails pace implementation of the Victorian government to provide nursing levels of care facilities for such as these is legendary in the history of gross discrimination and inaction by the Victorian government.
People with Disabilities domiciled with Aged Parent Carers.
No matter how you gloss it over, or dress it up, people with severe or profound dependent disabilities forced to live with aged parents are forced to live in ‘aged care’ facilities. There is no way around this argument…. If it is wrong for such people to live in aged care nursing homes, it is wrong for them to live with aged parents in the parent’s home.

Community norms dictate that the adult offspring will leave the family home and set up their own lives and living arrangements. For those who have a severe or profound dependent disability this is clearly not the norm.

Community norms dictate that the parents in a household will lose any rights over their offspring when they attain adulthood (usually at 18 years, but maybe even sooner if the child chooses to leave home). However, this is certainly not the case for the vast majority of offspring with a dependent disability.

Community norms and legislation allows for a working parent/partner to retire from the paid workforce at age 65 (at least) but this is not the norm for ageing parent carers who have a sentence of forced lifelong work until they drop or die.

Recommendation:
- That the Victorian Government provide ‘age appropriate’ nursing level of care facilities and ‘age appropriate’ supported accommodation services for all persons with dependent disabilities aged over 30 years as a matter of ‘First Order Priority’, and;

For people with profound disability aged less than 30 years where crisis or family breakdown is evident

➢ The Government’s response to and the methods for measuring unmet accommodation needs and how it can be improved:

The unmet and under-met needs for disability accommodation services is an ongoing and festering sore that will not heal, because government has taken the stance of an Ostrich with its head firmly in the sand. The clear evidence for this is seen in the changes the Department have made to the way in which they keep records for people waiting for a disability support services.

The advent of the Disability Bill 2006 was a classic manoeuvre to replace the Disability Services Act 1986, which required people with intellectual disabilities to have a General Service Plan (GSP), with an Act that requires no such plan. The onus is now upon the person with a disability to request a plan, thus the government can opt out of the planning process.

General Service Plans recorded the need for individuals to have supported accommodation and other services. This at least gave a future need view for many people with dependent disabilities. The method of keeping unmet need records was called a Service Needs Register (SNR amongst other things) which recorded both present and future need as Urgent, High, Moderate or Low needs. This at least gave some clue to likely future need for an accommodation service.

The advent of the Disability Bill gave the Department clearance to change the SNR to a new model called a Disability Support Register (DSR).

The DSR only records immediate need for a disability service. A very smart and devious way of getting the waiting list down to its smallest denominator! Therefore, it is clear that the Department has ‘NO Method’ of collecting Data on unmet need, under met need or future need for specialist disability accommodation and support services that in any way reflects the reality of decades of neglect in the system.
A classic example of the data collection to dampen demand is seen in the method used to collect information on respite services. Respite service delivery is measured in “episodes of Respite.” No-one really knows how this method of calculation was devised because an ‘episode of respite’ can be as much as a week (or two/four) in a Respite Group Home as long as it is consecutive use and within the same month, or, as little as 1 hour of in-home respite in a month.

What this method of data collection does is allow the Disability Branch of DHS to look as though they are increasing the number of families who have access to a respite service. A single family could use multiple episodes of respite over a year, whilst another family might only have 1 hour of respite in total. Clever, but deceptive and unfair and does nothing to measure unmet need or under-met need.

The method of collecting unmet and under-met need for accommodation services is just as sneaky by ensuring that only those with an immediate need will be recorded. The reality of waiting for a high needs supported accommodation service is that a person will have to wait many years for such a service and may ‘never-ever’ have their needs met.

(Even though the National CSTDA Minimum Dataset collection estimates the ‘potential population’ for access to these services, it does not measure the need or un-met need of any person who is currently not a service user. Therefore unmet need across the nation is a totally unknown quantity save for the ABS-SDAC and AIHW estimates of need.)

In the 12 months (from 30 June 07 to 30 June 08) people waiting for supported accommodation options in Victoria decreased by 3 persons (0.2 per cent) and those waiting for support to live in the community decreased by 12 persons (0.9 per cent).

The number of people recorded on the (DSR) as at 30 June 2007 is shown in the following table.

<table>
<thead>
<tr>
<th>Category</th>
<th>All Requests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Services Supported Accommodation options</td>
<td>1361</td>
</tr>
<tr>
<td>Support to live in the community</td>
<td>1294</td>
</tr>
<tr>
<td>Daytime activities</td>
<td>375</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3030</strong></td>
</tr>
</tbody>
</table>

The number of people recorded on the DSR as at 30 June 2008 is shown in the following table.

<table>
<thead>
<tr>
<th>Category</th>
<th>All Requests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Services Supported Accommodation options</td>
<td>1,358</td>
</tr>
<tr>
<td>Support to live in the community</td>
<td>1,282</td>
</tr>
<tr>
<td>Daytime activities</td>
<td>357</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2,997</strong></td>
</tr>
</tbody>
</table>

*The CSTDA Minimum Dataset 04/05 clearly articulates that no more than 7.8% of the Victorian potential population for accommodation services is in fact receiving a service.*

The AIHW report on Current and Future Demand for Specialist Disability Services puts the number of persons with a current unmet need for accommodation and respite at a minimum of 23,800, with a margin for error up to 31,700. (AIHW Current & Future Demand for Specialist Disability 2007)
As we have previously stated in this submission, there are over 13,600 people aged over 35 years with severe or profound dependent disability still living with ageing parents in Victoria. All of these people have a right to expect to have a home of their own in a caring society.

This number of persons aged over 35 years living with ageing parents take no account of those living alone who have under-met needs for support to live, nor does it capture those aged less than 35 years who could and should have a home of their own.

The ageing parents who care for older adult children have a right to expect to have an ‘empty nest’ and retirement with dignity.

Recommendation:

- The Victorian Government take immediate steps to establish a detailed Disability Accommodation and Support Service Needs Register in order to record accurately the current and future demand for Specialist Disability Services.

➢ Alternate approaches addressing unmet needs in disability supported accommodation in Victoria;

The Gippsland Carers Association, have long proposed the implementation of Population Based Benchmark Funding (PBBF) of Disability Services and have made this proposal to the Senate Inquiry into the Funding and Operations of the CSTDA. This option was also put to members of the Victorian and national Governments through a variety of means.

The strong case for PBBF has its origins in the fact that funding of aged care accommodation and in-home-support, has enjoyed this method of funding for decades. The Proposal is as follows:

POPULATION BASED BENCH MARK FUNDING IS THE FIRST ANSWER FOR DISABILITY SPECIALIST ACCOMMODATION AND SUPPORT SERVICES

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

This system is based upon a formula for growth funding, which currently funds service increases that maintain a ratio of 103 operational places and packages per 1000 of the population aged over 70 years, per annum. The planned ratio will increase to 108 places per 1000 population over 70 years, as part of the Commonwealth aged care strategy. [Dept Health & Ageing Fact Sheet 2005]

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 when ever agreements are renewed.

The CSTDA is a failure that deals out ‘cents’ off the budget table of both state and federal governments for people with disabilities; and it should be abolished.

The CSTDA:

- Is a continuous ‘bun-fight’ between the states and the federal government over Budget crumbs for disability services in a ‘feed the chooks’ mentality of lack of care for people with disabilities.

- There is no formula as the foundation for providing needs-based service increases and therefore no formula as the foundation for population-based bench-marked funding of services.
The future of disability services is unrelentingly grim, ageing parent-carers are struggling to cope and there are increasing numbers of persons with dependent disabilities who should be in their own supported accommodation facing eminent homelessness as parent Carers die.

Younger parent carers are struggling to cope with increasing severity of disability amongst sons and daughters who may previously have died.

Increases in disabilities such as autism with behavioural implications together with increasing financial stresses and work demands in the era of the two-income family are placing unpaid caring at extreme risk.

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

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

It would appear that the current Specific Purpose Payments Reform arrangements between both tiers of government may well be dismantling the CSTDA, but it also appears that nothing that guarantees growth funding in disability services is included in that reform.

**Why we need National Reform and Population Based Benchmark Funding**

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

**Parents as Co-Resident Carers of severely and Profoundly Disabled Australian persons aged less than 65 years.**

<table>
<thead>
<tr>
<th>Persons receiving assistance from a Co-resident parent, by age of person</th>
<th>Profound Core Activity Restriction</th>
<th>Severe Core Activity Restriction</th>
<th>Total Profound and Severe</th>
<th>Total with a reported disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-15 year</td>
<td>74,400</td>
<td>77,200</td>
<td>151,600</td>
<td>198,800</td>
</tr>
<tr>
<td>16-29 years</td>
<td>20,400</td>
<td>33,200</td>
<td>53,600</td>
<td>112,000</td>
</tr>
<tr>
<td>30 years and over</td>
<td>22,400</td>
<td>35,200</td>
<td>55,600</td>
<td>80,400</td>
</tr>
<tr>
<td>Total 0-30+</td>
<td>117,200</td>
<td>143,600</td>
<td>260,800</td>
<td>375,200</td>
</tr>
</tbody>
</table>

These national co-resident parent carer estimates, tell us that around 55,600 persons with a severe or profound disability were aged over 30 years in 2003 (**now over 35 years**) and are living with co-resident caring parents who provide assistance to them. Many of these parents are already aged in their 70’s, 80’s and 90’s. For Victoria this figure is 13,600.

**Population Based Benchmark Funding - addressing unmet need:**

In order to address the longstanding unmet needs pervading the current failed system, we require the introduction of **Population-Based Benchmark Funding** that Legislates to address that unmet need in the first instance and adopts a benchmark that will be sustainable in the long term and which ‘is seen to be’ eliminating the age-based barriers that pervade the current system.
The scope of the issue of population-based benchmark funding of disability services would seem to be overwhelming if it were to be applied in the same manner as that which currently exists to fund aged care, i.e. 105 places/packages per 1000 of the population aged 70 plus adjusted annually. This allocation is currently as set out in figure 2. below:

Fig 8. Based on population data and benchmarks - Report of Australian Gov Services 2006

<table>
<thead>
<tr>
<th>Pop 70+</th>
<th>% of total population</th>
<th>105/1000 benchmark for bed places or packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,892,800</td>
<td>9.3</td>
<td>198,744 places / packages (a)</td>
</tr>
</tbody>
</table>

(a) Aged care allocations of bed/packages is currently High care 40.8%, Low care 42.4%, CAPC’s 16.0% and EACH 0.9%.

To apply the aged care benchmark to adults aged between 15 and 64 who make up a 67% cohort of the general population we would come up with staggering figures as illustrated in Fig 9. using a simple 100/1000 benchmark.

Fig 9. Aged Care Benchmark funding allocation applied to Australians aged 15 – 64 based on ABS – DAC 2003 estimates

<table>
<thead>
<tr>
<th>Pop 15-64</th>
<th>% of total population (b)</th>
<th>100/1000 benchmark for bed places/packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>13,273,437</td>
<td>67</td>
<td>1,367,000 places/packages (rounded)</td>
</tr>
</tbody>
</table>

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

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

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

The S&P incidence Factor applied to Benchmark funding:
- The over 70 years of age incidence rate of severe/profound population is currently 22.5%.
- The 15-64 years of age incidence rate of severe/profound population is static on 3.9%.

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

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

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

This percentage allocation when applied to the people with severe/profound disability benchmark of 18/1000 becomes 1.8% per 1000 or approximately half of the severe/profound incidence rate of 3.9% for under 65 year olds.

Figure 10 shows the number of beds/packages to be applied to disability services utilising the 18/1000 benchmark as described above for:

Australia:

Fig 10. Australian Disability Population Benchmark utilising ABS – SDAC 2003 population chart 4430.0

<table>
<thead>
<tr>
<th>Pop 15-64</th>
<th>% of total population</th>
<th>18/1000 benchmark for beds or support packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>13,273,437</td>
<td>67</td>
<td>238,914 places / packages (rounded)</td>
</tr>
</tbody>
</table>

Victorian Government Inquiry into Provision of Supported Accommodation - Disability/Mental Illness - October 2008
Figure 11 shows the number of beds/packages to be applied to disability services utilising the 18/1000 benchmark as described above for:

**Victoria:**

<table>
<thead>
<tr>
<th>Pop 15-64</th>
<th>% of total population</th>
<th>18/1000 benchmark for beds or support packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>3,533,000</td>
<td>67</td>
<td>63,500 places/packages (rounded)</td>
</tr>
</tbody>
</table>

Note: The places/packages will be based upon the similar ratios to those in aged care with more emphasis on community access needs of younger people with disabilities, i.e. High care beds/packages 30% - Low care beds/packages 30%; and Community Access packages 40.0%. (Each category will provide for facility based and home-based respite as a priority for those who choose to continue in-home care)

This population based benchmark funding plan will dramatically increase the number of beds/packages in Victoria and eliminate unmet and under-met need. It must happen as a matter of justice. Governments must meet national obligations to care for our most vulnerable citizens and meet mutual obligations to the families that do care, out of love, obligation or because there is no choice.

There is an urgent need to support people with severe or profound disabilities to live separate lives and an urgent need to support distressed families who have waited far too long for alternative accommodation options for loved ones.

**Recommendation:**

- That the Victorian Government Legislate to introduce Population Based Benchmark Funding to Disability Services as a “First Order Priority”.

**Funding and costing the population-based benchmark model at current known expenditures for existing services:**

National average costs for accommodation support as estimated by AIHW 04/05 are as follows:

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

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

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

A benchmark for “low care” should sit somewhere between the upper and lower brackets and will be set at $45,000 for the purposes of this exercise (EACH equivalent). Clearly there is a demand for Hostel type accommodation as the numbers of persons inappropriately placed in aged care supported residential services (SRS) demonstrates.

The use of diversified and externally monitored options that make hostel living available to disabled people is not only sensible economically, but desirable to many people with disabilities themselves.

**The National Disability Benchmark Funding Formula**

For clarity we repeat the population benchmark for:

**Australia:**

<table>
<thead>
<tr>
<th>Pop 15-64</th>
<th>% of total population</th>
<th>18/1000 benchmark for bed places or support packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>13,273,437</td>
<td>67</td>
<td>238,900 places/packages * (rounded)</td>
</tr>
</tbody>
</table>
Application of the benchmark funding cost formula to the severe and profound Australian population aged 15-64 years

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

Now that you understand the reality of funding accommodation and support to the population of persons with a severe or profound disability due to the decades of neglect, we can look at the funding proposal for the implementation of benchmark funding in Victoria.

Victoria:

Fig 11(6). Victorian Disability Population Benchmark utilising ABS- population chart

<table>
<thead>
<tr>
<th>Pop 15-64</th>
<th>% of total population</th>
<th>18/1000 benchmark for beds or support packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>3,533,000</td>
<td>67</td>
<td>63,500 places/packages (rounded)</td>
</tr>
</tbody>
</table>

Fig 13. Victorian population Benchmark with High/Low and community care packages costs

<table>
<thead>
<tr>
<th>18/1000 benchmark of Pop 15-64</th>
<th>30% High Care beds/packages</th>
<th>30% Low Care Beds/packages</th>
<th>40% community Support packages</th>
<th>Total Recurrent</th>
</tr>
</thead>
<tbody>
<tr>
<td>*63,500 (rounded)</td>
<td>19,050</td>
<td>19,050</td>
<td></td>
<td>25,400</td>
</tr>
<tr>
<td>High Care $83,000 Per bed/package</td>
<td>$1,581,150,000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Care $45,000 Per bed/package</td>
<td>$587,250,000</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Community Care $18,800 per Unit</td>
<td></td>
<td></td>
<td>$477,520,000</td>
<td>$2,915,920,000</td>
</tr>
</tbody>
</table>

Note 1: For ease of demonstration, we will use a benchmark ratio of 30% high care accommodation; 30% Low care accommodation; and 40% community disability packages. Again, these packages will offer facility based and in-home respite as a part of each allocation.

Note 2: A Capital funding Program will also be required to ensure that innovative accommodation models are built to meet urgent demand and to provide for real choices made by disabled persons, including the right to choose not to be compelled to attend a day program because a person’s home is closed all day.

Note 3: The new system will also be required to make a provision for dedicated respite facilities, built to support long suffering families, with at least 6 weeks of respite annually for those who continue to care.

The cost of this proposal to introduce Benchmark funding clearly shows just how grossly under-funded the disability services sector is when compared to the current Disability budget allocation in Victoria of a little over $1billion per annum. There is currently a budget shortfall of 2/3 when compared to the aged care sector/disability equivalent benchmark formula.

The Commonwealth and the states have more than adequate resources with which to immediately commence the reform of disability services. Justice demands it to eliminate age discrimination. A fairer Australia will ensure that people with disabilities who are aged less than 65 years will no longer be discriminated against because the states have failed in their duty of care.

Recommendation:
- That the Victorian Government negotiate a Funding Agreement with the Commonwealth that will ensure the Commonwealth and the State each provide a fair share of the cost of implementing a full and fair Benchmark Funding Model to Disability Services for citizens aged less than 65 years.
The accessibility and appropriateness of supported accommodation for specific groups including rural communities, culturally linguistically diverse communities and indigenous Australians.

The current system of supported accommodation services clearly discriminates against people with dependent disabilities living in Rural and Remote Victoria. In Gippsland this means that accommodation services (group homes) are few and far between with 20 government and 15 non-government services in total. The maximum beds possible would be 210 if every service had six beds; however, some of these services have as few as two or three beds.

In 2004/05 the Gippsland region had supported accommodation (group homes) in Bairnsdale, Drouin, Lakes Entrance, Lucknow, Maffra, Moe, Morwell, Orbost, Sale, Traralgon, Warragul, Wonthaggi and Yarram. From the eastern most towns the distance between group home locations is an average of 80 KM across the region. (It is our understand that there are currently NO group home services in South Gippsland)

Gippsland has just 5% of the states population (229,500) but even at this minority status, population based benchmark funding would deliver 952 high care beds/packages, 952 low care beds/packages and 1,270 community care packages. This is a far cry from the existing service allocations and explains why so many 70, 80 and even 90 year old parents are still providing a 24/7/52 supported accommodation and care service today.

In March 2004 the Service Needs Register in Gippsland identified 270 people waiting for a supported accommodation services of which, 77 were rated as urgent and 81 high need. There are more people waiting for a supported accommodation service in Gippsland that have a service.

Facility based respite in Gippsland.

It is not possible to discuss the current supported accommodation system without talking about the number of facility-based respite beds available to families providing over 93% of all the supported accommodation and care. In Gippsland, the total number of adult respite beds for a potential population of at least 8,000 people with a severe or profound disability is still just a mere 18 beds in three (3) respite group homes located in Sale, Moe and Warragul only.

The critical issue for caring families is that access to respite group homes requires that the client have access to a day program save for gazetted holiday periods. This means that any family with a client who is not within Taxi or bus distance from a respite house, cannot have out-of-home respite in a group home.

Recommendation

- That the Government act immediately to increase the number of respite facilities available to ensure all primary carer families have access to at least 6 weeks of Respite per year.

The appropriateness of the current mix of service providers;

As previously discussed, the involvement of the Government Department in direct service provision is both discriminatory and grossly inappropriate. There can be no confidence for disability sector management, or for direct care staffing, in a dual supported accommodation system, where rule and rates of pay vary considerably in the Government and Not for Profit Sectors.

We clearly recall the government takeover of the Non Government Organisations (NGO’s) management sector in the 1990’s, which was justified on the grounds that services would be reconfigured and then ‘contracted out’. So here we are almost two decades on and the government is more deeply entrenched in direct service provision than ever before.
The institutionalisation of the group home system is largely due to this malady of the disability service provider sector. Government Departments do not have the hands-on approach of the local NGO where volunteer work and volunteer fundraising are commonplace in order to improve the lives of the people for whom they have responsibility.

For people with disabilities to be ‘included in community’ they need to be a part of the community. The local NGO was best at making sure that people with disabilities were included in their community. This is not true for many people living in departmentally managed services. No matter how good the staff is; in providing a caring environment, they cannot involve people in community if the bureaucracy that governs them restricts their capacity to fulfil this goal by i.e. not providing transport, recreation and leisure options, vacations, etc.

The same thing may be said, but to a lesser extent, for state-wide service provider involvement where management is at arms-length from the people they serve. Take the community out of the equation and you take the community out of the lives of people with disabilities. There is a very great need for new and innovative ways to involve local communities in the lives of people living in supported accommodation.

We believe there is a place for a wider range of options to be made available to people with dependent disabilities. Apart from the need to diversify the choices in accommodation options there is also a need to consider the involvement of more diverse NGO’s, the for-profit sector and the business sector in the mix.

We are aware that there are some for-profit providers of aged care village style living options who are building new projects with units specifically designed for younger persons with disabilities. The Karingal Green Project in Western Australia is a good example of this initiative where disabled and non-disabled persons live in units, hostel type accommodation, nursing level of care facilities and able housing side by side.

The city living lifestyles of people in Melbourne and its suburbs, have living choices that are available for all citizens and a full range of options are offered and utilised. These include condominiums, blocks of units, blocks of flats, town houses, Boarding Houses; stand alone houses and probably much more. Housing is offered by the private sector, by government and by individual investors in the rental market.

The critical question to be asked is “why is this OK for the so-called ‘normal population sector’ and the ‘aged care sector’ but not OK for people with disabilities?

Recommendation

- That the Victorian Government seek the diversification of service providers including the not-for-profit and for profit sectors to offer a wide range of supported accommodation choices to people with dependent disabilities with all options on the table.

The Process for Managing service quality

As previously discussed, we are of the firm opinion that one of the greatest failures of the disability supported accommodation service system stems from the fact that there are no external Monitoring and evaluation process. This is compounded by the fact that the DHS/Disability Services Division is at once the:

1. funding body,
2. direct service provider,
3. policy-maker,
4. planner,
5. and internal monitor,
6. and evaluator
For Disability Services to be accountable for the quality of the care provided to people with dependent disabilities it must have external and independent agencies responsible for:

1. accreditation of service providers,
2. monitoring of service providers,
3. evaluation of service providers and;
4. sanctions of service providers who do not comply with minimum standards

**Recommendation:**

- That the Victorian Government take immediate steps to introduce external and independent agencies for Accreditation, Monitoring, Evaluation and Sanction of all disability service providers to ensure a transparent and safe system of supported accommodation options exists and is maintained.

**Disability and Mental Illness**

Whilst we have made this submission based upon the needs of people with dependent disabilities and the families who care for them, we make it clear that we hold similar grave concerns for people with dependent mental illness who require access to supported accommodation.

The abject failure of the mental illness de-institutionalisation of accommodation process has created an underclass of citizens that is as bad as, if not worse than that currently available for people with severe and profound disabilities.

We do not claim to know all the nuances between the two systems, but we do know that families of people with mental illness suffer the same stress and anxiety over their loved ones as do those caring for those with disabilities.

What we do know is that the failure of government to plan, fund and provide adequate supported accommodation for those with dependent mental illness comes back to haunt families again and again.

Clearly a system of population based mental illness services would ensure that planning and provision of adequate resources was also made available in the sector.

**Recommendation:**

- That the Victorian Government act to ensure that a system of population based supported accommodation services with access to choices is created for people with mental illness.
Conclusion:

There are many families within our caring community who believe that the Victorian Government will not take our issues of discrimination and unfair treatment in the provision of supported accommodation at all seriously.

There are many more who believe that the volume and impact of the issues we raise concerning disability supported accommodation are already known to Government. They wish us to tell the Committee that the stresses and impacts of decades of caring without enough support have taken a wicked toll upon their lives and the lives of their families.

A Government, which chooses to ignore the ramification upon our families and those we care for is abrogating its duty of care to our most vulnerable citizens and placing our wellbeing at risk daily.

It is no accident that Surveys of Wellbeing, are now placing carers at the bottom of the wellbeing tree and at the top of the stress and health impact tree. The burden of caring upon thousands of families is real, most certainly unjust and will lead to families taking hard decisions not to care in the future.

People with dependent severe or profound disability have a right to expect that their government will ensure that as adult citizens they are assisted to have a home of their own.

People with severe and profound disabilities are treated as second class citizens because governments are not willing to provide the necessary funding for a quality of life that is equal to the minimum expected by the so-called normal citizens of our society.

A measure of the moral and ethical wellbeing of a society is in how it treats its least citizens. It is clear that the Victorian government just not meet this responsibility today.

Failure to provide adequate supported accommodation for people with dependent disabilities aged 64 years and under, clearly puts the state in breach of age discrimination laws because people aged over 65 with dependent disability do have access to government funded supported accommodation and choices in living options.

The impact upon families caring for those the government have neglected is crushing and unreasonable. This places the availability of future generations of families willing to care in grave jeopardy.

We ask that the Committee ensure the voice of caring families is heard above the clamour of Service Providers and Disability Self Advocates because we alone are in fact irreplaceable. The state and the nation cannot do without our collective $30.5 BILLION contribution to the nation’s budget bottom line in caring for citizens with dependent disabilities.

We are very pleased to have the opportunity to discuss the issues we raise with the Family and Community Development Committee and we trust the Government will see the need for immediate action upon our recommendations.

We trust that the Victorian Government will act to save the caring family system for future generations by accepting our recommendations in total.