11 November 2008

The Executive Officer  
Family and Community Development Committee  
Parliament House  
Spring Street  
East Melbourne Vic 3002

Dear Sir

Please find attached Carers Victoria's written submission to the Inquiry into Provision of Supported Accommodation for Victorians with a Disability or Mental Illness for distribution to members of the Family and Community Development Committee.

The submission elaborates and extends the content of our presentation to the hearing of the Family and Community Development Committee. We are happy to elaborate on any of the issues we have raised.

Carers Victoria believes that the provision of housing and support, both for people with a disability and for people with a mental illness is a key issue for unpaid carers in Victoria. Considerable investment by government over the coming decade will be necessary to ensure that the supply of supported accommodation is able to meet rapidly increasing demand.

Carers Victoria hopes that the Committee’s recommendations will address the issue of inadequate supply of supported accommodation for people with a disability or mental illness.

Yours faithfully

Maria Bohan
Chief Executive Officer

Attach
Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness

Family and Community Development Committee
Victorian Parliament

November 2008
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Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness
About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues. Last financial year, Carers Victoria provided over 20,000 direct services to family carers.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.
# Table of Contents

About Carers Victoria .......................................................................................................................... 2

Table of Contents ............................................................................................................................... 4

Section 1: Supported Accommodation for Victorians with a Disability ........................................ 5

1. Carers in Victoria ............................................................................................................................... 5

2. Current context ................................................................................................................................. 5
   2.1 Respite and social support ........................................................................................................... 6
   2.2 Medium and long term accommodation ....................................................................................... 6
   2.3 Falling between the gaps .............................................................................................................. 6
   2.4 Younger people in nursing homes ............................................................................................... 7
   2.5 Social and other support ............................................................................................................. 8
   2.6 Disability workforce ................................................................................................................... 8
   2.7 Service system interfaces ........................................................................................................... 9

3. Impacts ........................................................................................................................................... 9
   3.1 Carers of children and adolescents ........................................................................................ 9
   3.2 Carers of young adults .............................................................................................................. 10
   3.3 Older carers ............................................................................................................................... 11
   3.4 Carers of people with acquired catastrophic disabilities ....................................................... 12

4. Recommendations .......................................................................................................................... 13
   4.1 Accommodation options .......................................................................................................... 13
   4.2 Ageing carers ............................................................................................................................. 13
   4.3 Catastrophic injury insurance .................................................................................................... 14
   4.4 Information and support for families ....................................................................................... 14
   4.5 Planning for transitions ............................................................................................................. 14
   4.6 Service providers, staff and family inclusion .......................................................................... 14

Section 2: Supported Accommodation for Victorians with a Mental Illness ............................... 15

1. Introduction .................................................................................................................................... 15

2. The current context ........................................................................................................................ 16
   2.1 Mental health services ................................................................................................................. 16
   2.2 Housing options .......................................................................................................................... 18
   2.3 Homelessness and mental health .............................................................................................. 19

3. A more systemic approach ............................................................................................................ 20

4. Which models of housing and support work? ............................................................................ 20

5. Recommendations ......................................................................................................................... 21

References: Section 1 .......................................................................................................................... 23
References: Section 2 .......................................................................................................................... 25
Section 1: Supported Accommodation for Victorians with a Disability

1. Carers in Victoria

The 2008 Productivity Commission Report on Government Services shows that, in Victoria:

- Just over 4% of the potential population of people with disabilities accessed accommodation support services while 20% accessed funded community support services in 2005 – 2006.
- Of these service users, approximately 45% have profound limitations, 45% severe limitations and 10% moderate limitations.
- The proportion of people from culturally and linguistically diverse backgrounds accessing accommodation support services is lower than the proportion of the total population accessing them.

In Victoria there are over 990,000 people with disabilities of whom approximately 30% are considered to have a severe or profound limitation that inhibits their ability to care for themselves, communicate clearly or undertake normal cognitive or motor development tasks; and 690,000 unpaid family carers. These include 116,600 primary carers (Australian Bureau of Statistics 2004) who provide most of the support and assistance required for their parent, partner, child or friend with a disability or chronic illness.

These figures demonstrate that Victorian carers are currently providing the vast majority of support for people with severe and profound disabilities. They are under-supported by essential formal respite, accommodation and other services for which there is significant demand.

Finding appropriate models of support is critical for many carers of people with disabilities for several reasons. Knowing that there are suitable places where their family member can live as an alternative to caring at home is extremely important for the entire family. People with disabilities and their carers should have choices about where the person will live at various life stages and must be included in decision making processes which have such a major impact on their lives and futures.

Supported accommodation is far more than ‘bricks and mortar’. It requires ongoing, sustainable investment by government in the provision of flexible accommodation models, the workforce to implement such models successfully, and the support services that enable people with disabilities and their carers to enjoy the social connectedness that other Victorians take for granted.

2. Current context

At June 2008, the Disability Support Register had recorded 1358 people waiting for disability services supported accommodation options, including over 200 individuals with challenging behaviours or high levels of dependency as well as people whose family care situation is at risk or has already broken down. Another 1282 people are recorded as awaiting in home support to assist them to live in the community. (www.dhs.vic.gov.au)

The Victorian Auditor General (2008) has reported that the current system lacks capacity to address the recurrent crisis for people in need. It often resorts to unsustainable solutions and lacks alternatives to deal with the complex nature of people’s individual circumstances. Because the system often does not respond until a crisis occurs for the person and/or their carer and only interim support (e.g. respite care services) may be immediately available leaves carers and people with a disability in vulnerable circumstances.
The DSR does not provide people with disabilities or their carers with the capacity to register a future need for supported accommodation. This fails to capture data that would clearly assist DHS to plan for future accommodation needs and avoid the continuation of a crisis driven system.

2.1 Respite and social support

The Auditor General reports that, in some cases, ‘respite care was used to meet the accommodation needs of a person on the DSR awaiting Shared Supported Accommodation’. This raises serious concerns regarding the availability of regular respite for people with a disability and their carers.

‘Bed block’ is increasingly reported on an anecdotal basis by respite care providers and carers attempting to access respite services. Despite developing work by the Department of Human Services, the loss of respite places due to shortcomings in the provision of appropriate supported accommodation is a source of further stress upon carers. Such practices exacerbate the already desperate situations for some families who are only seeking some short-term respite but cannot do so because of the lack of places. (Senate Standing Committee on Community Affairs 2007)

2.2 Medium and long term accommodation

The needs of carers and the people for whom they care can change rapidly as a consequence of a family crisis, a breakdown in carer health or carer death. Thus it is essential that long-term care plans, emergency and succession plans are collaboratively developed and understood within family, social and professional networks prior to crises occurring.

Yet the current system lacks resources to effectively respond to supporting long term planning or managing crises. Carers often are required to accept whichever accommodation option is available regardless of the potential unsuitability of this for the person’s needs and aspirations.

The risks of inappropriate accommodation are enormous. Reactive, crisis-based decisions result in issues of incompatibility with other residents, geographical dislocation from family members and other social and vocational supports, a lack of appropriate staff skills and eventual placement breakdown. The Community Visitors Report 2008 identified further issues for residents who are initially accommodated but, when needs change and incompatibilities arise, are unable to move to more suitable housing, as there are no other options available to them.

2.3 Falling between the gaps

Unmet need is also an ongoing concern for carers of people whose disability is either not so severe or not known as to warrant ‘crisis’ intervention but still has detrimental impacts upon their decision making capacity.

In 2002–2003, Victoria had 8,050 clients in the Supported Accommodation Assistance Programme (SAAP) ‘disability’ client group, 26.4 percent of the overall SAAP client group. This client group received specialist services less often than the ‘non-disability’ client group, suggesting that SAAP may not always be able to cater for the specialised needs of people who are homeless with a disability. (Australian Institute of Health and Welfare 2005)

Within this group of SAAP clients are people who experience cognitive disabilities that seriously affect their decision making capacity but are labelled “high functioning” or “mild”. These disabilities can include foetal alcohol syndrome, acquired brain injury, autism spectrums or other forms of cognitive disability. The application of such labels to them can minimise the significant daily challenges these people face and their complex support needs.

This may result in their exclusion from appropriate service and support, in favour of people whose disability and support needs are recognised and described as profound (O’Connor and McDonald
2008). The present crisis in supported accommodation results in 'rationing' of services that increasingly excludes people with moderate to mild levels of disability. They are unable to afford private housing; experience long waiting lists for public housing and risk dislocation from family members and other social and vocational supports if eventually allocated a residence.

The lack of suitable accommodation options often results in carers, guardians or caseworkers resorting to private providers including Supported Residential Services (SRS), hostels and boarding houses. Support services are few and people with a disability are vulnerable to abuse and exploitation as reported by the Senate Standing Committee on Community Affairs (2007).

This type of accommodation may appear relatively affordable but simply replaces the person's original residency in segregated institutions with another congregate model. Of greatest concern is that private facilities lack the supports and external activities required for residents to successfully live socially inclusive lives. Hence, models such as boarding houses and SRSs do not represent de-institutionalisation but rather serve only to re-institutionalise people. (Shelter NSW 2000)

Failure to subject SRSs and other private facilities to the same legislative and industry accreditation requirements as funded disability-specific services can result in residents experiencing conditions that would never be tolerated elsewhere:

- Unskilled workforces where staff do not have the requisite skills, qualifications and ongoing professional development to provide effective support to residents with complex (and less complex needs).

- Inappropriate gender mixes of residents which may leave vulnerable female residents at risk of harassment and assault by male residents.

- Inappropriate mixes of health conditions and challenging behaviours which are left untreated, and may place vulnerable residents at risk of assault by other residents.

Lack of individual care plans and activities, and a paucity of health resources all contribute to the high level of risk confronting residents of supported residential services. They may be marginalised, vulnerable, and unable to seek alternative services from another provider due to the shortage of accommodation for individuals with disabilities. (Maughan and Sparrow 2005)

2.4 Younger people in nursing homes

The lack of suitable supported accommodation options for younger people (aged less than 65 years) whose disability is due to catastrophic injuries or neurological conditions results in many residing in aged care facilities.

Aged care facilities are not designed to cater for the very different and more intensive needs of younger people with disabilities. (Young People in Nursing Homes National Alliance 2008).

- Staff do not have the requisite skills and knowledge to care for younger people with Acquired Brain Injuries; and are not trained to deal with the specific care needs of other disabilities, such as Multiple Sclerosis, Muscular Dystrophy or Parkinson's disease.

- Rehabilitation is not provided and there is a lack of financial resources needed to purchase appropriate equipment to support the complex care needs of young people.

- Therapeutic input resources needed to sustain an individual’s physical, cognitive and social functioning are largely unavailable. So too are the resources needed to foster that individual’s rehabilitative potential.

- Staffing levels are insufficient to maintain and promote independence or community participation.
Additionally, the placement of these young people in nursing homes leaves them without appropriate peer and other social contact due to the isolating nature of their placement with older residents. They are unable to access educational, training or employment opportunities that are more readily available to their peers who live either in the family home or in specialist disability supported accommodation.

The emergence of new accommodation models through the ‘my future my choice’ programme is a welcome improvement. However, a substantial gap still exists between demand for and supply of smaller, age appropriate, specialist disability supported accommodation. Stronger investment in this area of supported accommodation needs not only addresses the needs of young people currently resident in nursing homes; it also alleviates the waiting lists for older people requiring nursing home care.

2.5 Social and other support

People with disabilities very rarely have only a need for housing. They also have a need for various levels and types of support across their needs and aspirations in many life areas – employment and day programmes, recreation and social support.

According to Ramcharan, Nankervis and Abdilla (2007), research strongly indicates that support systems must be in place to enable a person with disability to achieve successful outcomes in their community life. Housing and support are not independent of one another – they must be planned and coordinated together and in accordance with the person’s changing needs (Bigby and Fyffe 2007). They must complement each other so that good outcomes can be reached on a holistic basis.

In a report to the Victorian Department of Human Services, the Centre for Developmental Disability Studies states “Although it is critically important that suitable housing be available the more important issues are the specific processes that lead to clearly defined quality of life outcomes” (Parmenter and Arnold 2008).

Yet, Community Visitors to residential facilities continue to identify major deficiencies in the development of plans that enhance residents’ aspirations for physical, social, emotional and intellectual development and wellbeing as required by the Disability Act.

The interface between supported accommodation and other services and funding programmes must be co-ordinated and complementary. A lack of policy and practice integration undermines linkages between health, housing and cared accommodation services - causing inefficiency and cost shifting, and uncertainty and confusion for carers.

2.6 Disability workforce

Challenges identified on a national level regarding disability workforce issues transpose to the Victorian sector and have particular implications both in the present and for the future. A report prepared for the National Disability Administrators in 2006 found:

- Changes in disability policy directions are impacting on the way in which services are delivered i.e. from institutional care to community care and social inclusion.
- Advances in medical and allied health technology have extended the lives of people with disability or chronic illnesses.
- Disability support occurs in a range of environments rather than within one place of residence.
- Service users are increasingly well educated about the types of services available to them and have higher expectations regarding service quality and standards.

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness 8
At present, Victoria’s disability sector is struggling to provide staff with the requisite skills and approaches to best meet changing trends in policy and expectations of people with a disability and their carers. Poor salary levels, low recruitment and retention rates and funding constraints for professional development and training prevent the sector from addressing the issues listed above, resulting in lesser outcomes for clients.

2.7 Service system interfaces

“What happens when you have an intellectual disability and the services that once provided for you in your youth and middle age no longer meet your needs?” (Disability Services Australia).

In 1997 the concept of “ageing in place” was enshrined in the Aged Care Act. This legislated that people could remain in their home with support (however defined) regardless of their increasing care needs. Disability services alone cannot meet all the needs of people with a disability. Levels of access to generic services, such as aged care, health and housing, can affect levels of demand and unmet demand for services. People may need complementary combinations of support from both the disability and aged care service sectors.

Yet, this is made difficult by artificial and rigid program boundaries and inadequate funding. For example, ageing parent carers have found that separate funding programs, the lack of collaborative planning between Commonwealth and State governments and the impact of competition policy have led to:

- Increases in the fragmentation of services targeted to ageing parent carers;
- Considerable confusion among carers about whom to approach for what and about perceived duplication between programs;
- Unnecessary restrictions on program eligibility. These have excluded some needy ageing parents; and
- Poor recognition of the need to support ageing parents and their families with planning and implementing future care arrangements.

Research by the Australian Housing and Urban Research Institute (2002) revealed that a fragmented approach to delivering housing and support services for adults with disabilities makes for unwieldy, costly and sometimes unfair service provision. In the report, it is recommended that common approaches be established between the Commonwealth and States and within State-based policy and programmes involving urban planning, housing, social welfare, health and disability support.

According to ACROD (2005), “Among governments, progress towards this objective has been impeded by bureaucratic barriers, suspicion of cost-shifting and a lack of co-operation between the States and Commonwealth – and even between departments within a single government”.

For carers and the people they care for, seamlessness of policies and programmes must occur across government departments and between governments, federal and state, to ensure individual, community and economic benefit.

3. Impacts

3.1 Carers of children and adolescents

Professional and government opinion has changed about where children with severe disabilities and high support needs should live. Previously, families were encouraged to place their children in
an institution and to "forget" them. The objective now is for children with severe disabilities to live with a family - preferably their birth family but, failing that, an adoptive or foster family.

Supportive strategies, which enable people with disabilities to remain within supportive environments, must commence from early childhood. However, the costs of caring for children with special care needs are high because of their greater requirements for primary and specialty medical care, as well as therapeutic and supportive services such as rehabilitation, aids and equipment, allied health needs and respite care.

Issues raised earlier in this submission regarding respite care and other unmet need apply just as strongly to Victorian children and adolescents with a disability as to adults. There is much anecdotal evidence that out-of-home respite care is usually difficult to access. To access appropriate respite and longer term accommodation support, carers are forced to demonstrate their needs through traumatic means i.e. failing to 'collect' their child from respite, notification to the child protection system or relinquishing guardianship.

Where children with a disability enter the child protection/ substitute care system due to family crisis or breakdown, expenditure to maintain the child's placement far outweighs the costs associated with the provision of suitable pre-emptive support services including respite and other supported accommodation options.

Recurrent expenditure on child protection and out-of-home care services was at least $1.4 billion across Australia in 2005-06. Nationally, out-of-home care services accounted for the majority (61.9%, or $479.4 million) of this expenditure. A study by the Social Policy Research Centre (McHugh, 2002) found that the cost of caring for children in foster care is, on average, 52% higher than the costs of caring for children not in care.

Early investment in the provision of appropriate respite and other supports to children with a disability and their carers – in home and out of home – has a longer term financial benefit to government and the community and ongoing social and emotional benefit to the person with a disability and his/ her carers. The loss of guardianship and, subsequently, participation in planning and decision – making can only have detrimental impacts on carers, their child with a disability and other family members.

3.2 Carers of young adults

For all young adults, there are a range of needs to be met which can enable them to realise their aspirations and future plans - income, accommodation, vocational / educational choices, community participation, recreation and transport. Young adults with a disability have these same needs as their peers yet their transition from childhood to adolescence then to adulthood is frequently more complicated.

Like all young adults, many people with disabilities desire independence and believe that leaving home signifies a major step into adulthood. For young people with disabilities, it is essential that transitional planning be implemented from childhood through adolescence and into young adulthood. Sound planning through family centred approaches can address issues which may impact upon the young person's ability to move from the parental home to other types of accommodation if that is their wish.

In one of very few research projects on young people with disabilities and their housing aspirations, Dean (2003) concluded that accessible information that can inform decision making by both the young person and carer is required. This needs to:

- be available before the young person is of an age to leave home and considered regularly in future plans
- assist the individual and carers to think about what represents good housing

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness

10
• explain how to find out about local options
• indicate which agencies would be able to answer questions, provide support and advocate if required
• consider all living options — staying with parents, living alone, living with a partner, sharing with friends and group living
• cover all tenure options — mainstream and specialist social housing providers, private renting and owner occupation.

All life transitions for young adults require attitudinal change by parents and other family members; for young adults with a disability, the transition is often accompanied by greater risks (real or perceived) than for their non-disabled peers. For the young person and carer, family centred approaches to transitional planning are more likely to engender successful accommodation outcomes than if carers are excluded or marginalised in decision making.

3.3 Older carers

The effect of the current crisis in supported accommodation upon carers is, at the least, stressful but can also be traumatic, particularly for older parent carers as noted by the Auditor General who found that carers were ageing and in need of support themselves.

There are many carers over 65 who have significant health issues and grave concerns about the future of their son, daughter or other relative. Older carers of adult sons and daughters have usually been caring a long time, sometimes as long as 50 years. At the same time, there is limited state wide planning data about the current needs and circumstances needs of ageing parent carers in Victoria. Data about parent health and capacity to continue; access to formal and informal supports and expressed future needs and preferences does not appear to be systematically collated and maintained.

It should not be assumed that informal and ongoing family care will be available or desirable when the long term primary carer is no longer able to care. There are now clear expectations that people with disabilities will continue to live in the community with informal and formal support unlike previous generations who were unlikely to outlive their parents and were likely to be cared for through institutional arrangements.

The balance between planned, supported transition from parent care and ensuring that there is capacity within the system for emergency or sudden transitions for people with disabilities requires well resourced service providers and adequate government funding. This is a weakness in the current system as detailed in the Victorian Auditor General’s report. It must be urgently addressed by both the Victorian Government and through the Commonwealth States and Territories Disability Agreement. The recent injection of Commonwealth and State funds into the system for supported accommodation, respite and transition support is welcomed but will clearly be insufficient to address the gap between demand and supply of the key services needed by ageing parent carers.

Transitional approaches to supported accommodation for people with disabilities require the provision of carer support services which are proactive and prevent families confronting unexpected crises without the ‘safety net’ of appropriate accommodation options. Carer support services need to be proactive and skilled in working with families to plan for emergency and longer term needs of the person with a disability.

Research and practice wisdom demonstrate that ageing parent carers can be ambivalent about and reluctant to engage with planning for the future. Together with their families and the person with a disability, many parents need support to plan for transitions to care outside the family home. The process should be empowering and involve ongoing and supported processes of discussion. It should maximize:

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness 11
The choice of families and people with a disability about where the person with a disability should live, in what sort of housing, with whom and with what support.

Opportunities to consider the possibilities of combining formal and informal supports and resources and private, public or supported housing options for the future care of the person with a disability.

Access to specialised and skilled support in relation to emergency care planning, wills, trusts and estate planning and planning transitions to alternative accommodation.

Assistance for families in developing an understanding of formal guardianship and financial administration systems

Encouraging relatives and friends to continue their involvement with the person with a disability where feasible. (Carers Australia 2008)

There is a need to consolidate existing programs and resources for ageing parent carers into a program of 'Planning for the Future', which ensures the needs of ageing parent carers are systematically and proactively targeted. This could build on the recent funded Disability Assistance Package for ageing parent carers. Growth funds can be utilised to consolidate infrastructure and resources to address key areas of need. These include:

The need for a state coordinated and regionally implemented interagency Register of Ageing Parent Carers and Outreach Support Service. This would register ageing parents and maintain consistent planning data about family needs and circumstances and the needs and circumstances of the person with a disability.

It would also register key contact workers or case managers who identify and engage with ageing parent carers, regularly monitor and review their circumstances and needs, and negotiate access to needed and available in home and respite support services.

A register would reassure ageing parent carers that their needs and circumstances and future plans were known to service providers and the Department of Human Services.

A Planning for Future Housing Support Service which targets ageing parent carers with high priority needs for support with the transition of their son or daughter to alternative care.

Skilled transition support workers/accommodation planners would actively engage with people with a disability, their ageing parents and families to plan and develop individual and group plans for future shared and supported accommodation or community housing.

Selected providers would be contracted to develop the variety of housing options required.

The impact of the current crisis must be addressed through improved provision, flexibility, choice and quality of respite and permanent accommodation options as well as effective support services which enable people with disabilities and their carers to make well informed decisions regarding the future.

3.4 Carers of people with acquired catastrophic disabilities

There is considerable government and stakeholder support for the development of national no fault catastrophic injury insurance scheme and for an expansion of the scope of current provisions. Needs and cost modelling through Price Waterhouse Coopers indicates that the proposed initiative is achievable and will reduce some of the inequities for people who acquire disabilities as a result of traumatic injury. It would free up a number of high cost care packages currently allocated to non compensable people.

A life-time approach to care which ensures early intervention, inclusive planned and personal support services, and aids and equipment for people with a disability can provide carers with more confidence that ongoing needs for support and assistance can be met. An expansion of current disability insurance schemes offers financial, emotional and material benefits that can greatly alleviate the enormous pressures carers face.

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness 12
However, planning of such a scheme needs to address the needs and rights of carers particularly where there are issues about the decision making capacity of the injured person. Consideration needs to be given to the needs of family carers for respite and support and to the role of family carers as partners in needs assessment, care planning and care management.

Where families provide a considerable amount of care and support, family centred planning should include monitoring the needs and rights of children in the care situation as well as monitoring the needs of family carers and their health and well being. Duty of care to unpaid carers should be a consideration.

4. Recommendations

4.1 Accommodation options

• Significant investment must occur to expand the development of shared supported housing, shared and mixed equity housing models and other forms of supported community housing packages for high priority people with a disability.

• Increased investment in supported accommodation for people with a disability requires increasing the capital stock and mix of houses and apartments for individuals, couples and small groups. This should be accompanied by increased investment in packages of staff support for community living.

• Increased investment in out of home and in home respite and support services is required. It must be based on the needs of the individual with a disability and the family. Expanded numbers of targeted Individual Support Packages are required to support high needs care situations throughout the lifecycle.

4.2 Ageing carers

• An increased allocation for flexible in-home and respite support packages is required to ensure that ageing parent carers with health or frailty issues can continue to care for the person with a disability at home for as long as they wish to.

• Increased funding to the Disability Assistance Package to allow the development of a state coordinated and regionally implemented Register of Ageing Parent Carers, and Outreach Support service. This would:
  
  o Register ageing parents, monitor their health and well being, and ensure their access to available support services. It would maintain consistent planning data about family needs and circumstances and the needs and circumstances of the person with a disability.
  
  o Rationalise and register key contact workers or case managers who identify and engage with ageing parent carers, regularly monitor and review their circumstances and needs, and negotiate access to needed and available in home and respite support services. Families and significant other people would be encouraged to develop current support plans, emergency care plans, financial plans and long term care plans for future transition.

• Development of a Planning for Future Housing Support Service to work over time with ageing parents, the person with a disability and other family members to plan and develop individual and group plans for future shared and supported accommodation or community housing. Selected providers would be contracted to develop the variety of housing options required.
4.3 Catastrophic injury insurance

- A planned expansion of the no fault catastrophic disability insurance scheme through modest increases of motor vehicle levies in Victoria.
- Clear policy development on the role and needs of unpaid carers and family members of recipients of catastrophic injury insurance.

4.4 Information and support for families

A comprehensive support framework for family carers should contain the following aspects:

- Timely, accessible and relevant information that is culturally and linguistically appropriate and targeted to people who it will reach
- Emotional support to assist carers dealing with a range of changing emotions including guilt, fear, frustration, isolation, loss, anger, depression, anxiety
- Education and training to equip carers with practical skills for management of the disability or condition, communication and coping skills
- Effective and sufficient respite to give carers substantial breaks from caring responsibilities
- Financial assistance to meet costs of equipment and aids, allied health needs, specialist medical support.

4.5 Planning for transitions

In order to be effective, it is essential that transitional programmes address:

- The choice of families and people with a disability about where the person with a disability should live, in what sort of housing, with whom and with what support.
- Opportunities to consider the possibilities of combining formal and informal supports and resources and private, public or supported housing options for the future care of the person with a disability.
- Access to specialised and skilled support in relation to emergency care planning, wills, trusts and estate planning and planning transitions to alternative accommodation.

4.6 Service providers, staff and family inclusion

Reliable and consistent staff and inclusive management of facilities are extremely important to achieving positive outcomes for families and people with disabilities:

- Quality, reliability and availability of support and clinical staff are extremely fundamental to the success of any supported accommodation model.
- The most effective models of supported accommodation are those that allow flexibility in the delivery of care services to cater for the different lifestyles and needs.
- Carer involvement must be incorporated in the provision of supported accommodation.
Section 2: Supported Accommodation for Victorians with a Mental Illness

1. Introduction

Accommodation is a key issue of concern for carers of people with a mental illness. A 2007 survey by the Mental Illness Fellowship of consumers, carers and professionals rated housing as their biggest area of concern.

People with mental illness have been living in the Victorian community in large numbers since deinstitutionalization occurred in the late 1980s and 1990s. There is strong evidence that with adequate housing and support, this can occur successfully, even for those with relatively high needs (Arthorson and Worland 2007). However, there is an increasing sense of urgency because current levels of housing and support are inadequate. The affordability of housing in the private sector has declined sharply in recent years. As a consequence, house purchase and rent prices are of reach for people with mental illness who are often on low incomes. There has been a simultaneous decline in levels of funding for public housing. Between 1995 and 2006, there was a net reduction in public housing stock in Australia (Productivity Commission 2008).

There is a lack of adequate data about the extent of demand and unmet need for housing and support for people with a mental illness (Bleasdale 2007). The mental health system is extremely complex and is fragmented, with different parts of the system having different data systems. People with mental health problems may use several parts of the system or none of them, or may be deterred from accessing services with long waiting lists. The shortage of housing and support services are apparent because of their effects on other systems. For example:

- An estimated 30% of Australia's homeless population has mental health problems (Chamberlain et al 2007)
- Between 2001-06 there was a 43.2% increase in the number of people with mental illness living in rooming houses (DHS, 2008a)
- A recent Review of the Regulation of Supported Residential Services (SRS) found that 58% of pension-level SRS residents have a psychiatric disability. (DHS, 2008b)
- 46% of acute mental health inpatient beds in Victoria are blocked (Boston Consulting Group 2006). This is caused, at least in part, by a lack of downstream, sub acute supported accommodation options. It affects the throughput of the entire mental health clinical system.

It is debatable as to whether deinstitutionalization policies in Victoria have adequately catered for the provision of secure accommodation and support. It is common for carers of people with a mental illness to feel that they are expected to make up for the system's inadequacies (MHCA 2005), a stance confirmed by international studies (eg. Schene, A. et al, 1996). Although many family members who care for a person with a mental illness may not cohabit with them, they continue to provide emotional and financial support, advocacy and crisis accommodation. In particular, they provide crisis accommodation and care for their relative when symptoms of illness emerge or when their relative is discharged early from an acute or clinical setting. A lack of access to suitable ongoing accommodation options impacts on the entire family. For example, if an adult with a mental illness is forced to remain living with their family because of a lack of other options, this can adversely affect the independence and well being of all household members. Again, there is little current data to reflect the true extent to which this situation occurs.

Anecdotally, there is a growing cohort of ageing parent carers of people with significant mental illness who are profoundly concerned about the lack of available housing and support for their son and daughter when they are no longer able to provide care and support. They may have provided emotional and financial support, advice and assistance for a lifetime; either caring for their offspring in their home or providing back up support and crisis intervention when their offspring live. 

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness
elsewhere. They are concerned about who will care in the future when due to frailty, ill health or death they cannot continue; a dynamic that creates further stress if their son or daughter is socially isolated or has experienced significant breakdown in informal relationships.

There has been little systematic research undertaken in Australia concerning the needs, experiences and concerns of ageing parent carers of people with significant mental health issues; and little consideration given to how their sons and daughters can be supported in the future. This matter must be urgently addressed.

2. The current context

There is no single system that provides housing and support for people with mental health problems. Consequently access to housing and support requires negotiating between a confusing combination of mental health, homeless and housing services.

2.1 Mental health services

Victoria’s current mental health system provides a spectrum of services for people with serious mental health problems. These range from acute inpatient services through to clinical services that provide community outreach. Psychiatric Disability Rehabilitation Support Services (PDRSS) are designed to assist people with mental health problems to recover in the community (See Figure 1).

Figure 1: Core Mental Health Services in Victoria

Source: Because-Mental Health matters, DHHS (2008), modified from Improving Mental Health Outcomes in Victoria: The Next Wave of Reform [2006]. The Boston Consulting Group

Carers Victoria: Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness
Some key observations can be made about the system. First, the system is extremely complex, with different assessment and eligibility criteria for different service types. This makes access to the system problematic. Second, the total number of state funded beds (clinical, forensic, PDRSS etc) is relatively small (1965 persons) compared to the 47,000 persons (Boston Consulting Group 2006) receiving state mental health services each year. This ratio is not altogether surprising as since deinstitutionalization, Victoria’s mental health system has been intentionally geared towards treating people in the community rather than in hospitals or residential facilities. It is worth noting that around 56% of Victorians with mental illness do not receive any mental health services at all because of systemic access problems. They would not be represented in these figures (BCG 2006).

The lack of mental health beds raises questions of where people with mental illness live and what support they need. For a community based system to succeed, it is necessary to provide a range of levels of support to meet the diversity of needs that exist in the population.

The current clinical mental health system aims to achieve this through providing a continuum from the high levels of care provided by acute inpatient units, to Secure Extended Care Units (SECU), step up-step down units (Prevention and Recovery Care, or PARC services), Community Care Units (CCUs) and outreach clinical supports such as those delivered through Mobile Support Teams (MST). Non-clinical support services have a parallel continuum provided by Psychiatric Disability Rehabilitation and Support, or PDRS services. These include Residential Rehabilitation Services, Home Based Outreach Services (HBOS) and Intensive Home Based Outreach Services (IHBOS).

In practice, people with mental illness usually need both clinical treatment and psychosocial rehabilitation and support in order to recover and function well in the community. Thus many clients access both clinical and PDRSS services. Much work has been done to assist the two sectors to work more closely with each other. Indeed, PARCs, a relatively recent service type, is a hybrid model that includes both clinical and PDRSS elements.

There are a number of ways in which the mental health system is failing to meet its objectives. The Boston Consulting Group’s Report, “Improving Mental Health Outcomes in Victoria: The Next Wave of Reform”, (2006) provides an analysis of the lack of access to acute services in particular. The report’s findings show that many acute beds are not accessible because they are blocked. People are remaining in them when they no longer need to because appropriate lower levels of support, and frequently accommodation, are not available. Frequently the lower level treatment and support services are also blocked. Good mental health practice requires interventions are as normalized as possible for therapeutic and rehabilitation reasons. It can be counterproductive for individuals to spend longer than necessary in hospital or similar settings.

System problems can also be considered through an economic efficiency lens. Acute adult inpatient beds (metropolitan) cost $512 per day (DHS 2008c). They represent the most expensive treatment option for the already stretched mental health dollar. By comparison, Residential Rehabilitation Services cost $139 per day. (DHS 2008c)

The Boston Consulting Group Report makes a number of recommendations to address the issue of inadequate system throughput. These include a greater investment in long term, secure supported housing and greater investment in Psychiatric Disability Rehabilitation and Support services for people with mental health problems. Similar recommendations were also developed through the Victorian Government’s own analysis. (DHS, 2007)

Adequate post acute or "downstream" supports are essential to relieve pressure on the acute system. In addition, adequate community support services can ensure the availability of responsive support before people become acutely unwell. It is frequently reported that Victoria’s mental health system is crisis driven. If people with mental illness and their families were able to
access improved early intervention support and assistance in the community, in the settings of their choice, there would be less pressure on and greater access to the clinical acute end of the system. This intuitive finding is also supported by the methodical modeling approach undertaken by Gavin Andrews and his Tolkien II team (Andrews 2006).

Clearly there is a need for greater investment in Psychiatric Disability Rehabilitation and Support services and in housing. Current state government spending on PDRS services makes up less than 10% of total mental health spending, and has done so for several years. (DHS 2008c)

There are other significant gaps in the continuum of supports needed for a successful mental health system. Prevention and Recovery Care services (step up and step down) have been a welcome addition here, meeting the needs of those in “sub acute” clinical phases. They provide significant assistance to caring families when the person for whom they care is not ill enough to access an acute care bed, or when the person for whom they care is not yet well enough to return to the community. Currently the number of PARC beds is extremely limited. There is a need for a more extensive state wide roll out of these services and a greater emphasis on their ‘step up’ function.

There are currently 330 Residential Rehabilitation beds spread unevenly across the state. They provide either 9am to 5 pm or 24 hour support. They are in short supply. Alternative outreach models of psychosocial support are also inadequate. Intensive Home Based Outreach Support and Home Based Outreach Support services respectively provide an average of just 3 hours and 1.5 hours of support to each client with a mental illness per week. This level of support is clearly inadequate for many people with a significant mental illness.

The State Government introduced a new initiative in 2006-07 (Integrated Rehabilitation and Recovery Care Service, or IRRCS) to support long stay and complex need consumers from Secure Extended Care Units and Community Care Units. It provided high levels of care through coordinated clinical and PDRSS service, with the intention of filling a support gap between residential and outreach services and to address part of the problem of blocked beds. This initiative is currently being evaluated, but anecdotal evidence of its efficacy is promising. The initiative was only initially funded to support 12 individuals.

More programs of this sort are necessary to ensure a continuum of sub acute services. Excellent initiatives such as the New South Wales Housing and Support Initiative (HASI) can be systematically developed in Victoria to support people with complex needs. HASI program outcomes for individuals, families and service systems are impressive (Muir et al 2007). HASI incorporates two levels of support; High Support which allows for up to 5 hours of support a day, and Lower Support, which allows for up to 5 hours per week (NSW Department of Health 2006).

2.2 Housing options

People with mental health problems may live in their own homes, live with their families, live in rented property or public and community housing, or live in prisons. Some people with a mental illness are homeless. People with mental health problems are over represented in homeless services. Data also suggests that 28% of newly remanded criminals suffer from some level of mental illness (Referral decision scale as cited in Boston Consulting Group Report, 2006).

People with mental illness experience significant disadvantage in purchasing their own homes or accessing private rental accommodation. They have much lower levels of workforce participation than the general population (ABS 1998). This results in low incomes that prohibit purchasing or renting housing in metropolitan areas, even though people with a mental illness may prefer to live in inner metropolitan areas which are close to essential health and support services. Many people with mental illness also express a preference for single accommodation which is particularly expensive and in short supply in the current market. People with mental illness may also experience discrimination when seeking private rental accommodation (SANE Australia, 2008).
Priority groups for public housing include those with a history of homelessness and those who have support needs such as mental health problems. However, recent funding for public housing has reduced in real terms, with the number of public housing dwellings in Australia falling from 365,000 in 1995 to 339,771 in 2007 (AIHW, Homeless Green Paper submission, 2008, Productivity Commission 2008). This means that there are currently 5755 people in Victoria waiting for early priority housing (DHS, 2008d).

Public housing estates can readily become areas of ‘concentrated disadvantage’. This in turn increases the stigma of public housing (Jacobs and Arthurson, 2003). It may have adverse consequences for those who are particularly vulnerable and who require a supportive environment to recover from their mental illness.

People with mental illness can also access community housing. There are currently eight registered housing associations which develop, own and manage rental housing for low income Victorians. They have a history of successfully providing long term secure housing for people with disabilities, including those with mental illness.

The Victorian Government supported the growth of community housing with an allocation of an additional $300 million in 2007-08 (Department of Treasury and Finance, 2007). The government aimed to increase housing affordability for low income people through promoting the growth of housing associations. However, government policy requires housing associations to demonstrate growth in their housing investments. This provides perverse incentives for housing associations to house low income families rather than those who are income security dependent and most in need. There is a disincentive to house people on income security who can only afford minimal rents. (Connellan 2006). The State Government’s housing growth policy has the potential to undermine the capacity of housing associations to provide low cost homes to people with disabilities.

People with mental health problems also have the option of accessing privately owned boarding houses and Supported Residential Services (SRRs). There are 187 registered SRRs in Victoria, and 6361 registered beds (DHS 2008b). Services provided by SRRs’s usually include meals, laundry, care and assistance with activities of daily living. Access to on-call staff is a minimum requirement. There are two broad sub-categories of services; pension level, meaning that bed are provided for a fee of the pension plus Commonwealth Rent Assistance, and above pension-level facilities that charge more. In effect, residents are required to pay for their support, a requirement that does not exist in publicly funded supported accommodation services.

The Review of the Regulation of Supported Residential Services in Victoria confirmed that the proportion of residents with a psychiatric disability had increased from 45% in 2003 to 58% in 2005 (DHS 2008b). Given the minimal levels of support provided, these figures are of great concern. They represent a failure of the supported accommodation system to address the needs of people with a mental illness. SRRs do not have a rehabilitation focus, although SRR residents would be eligible for clinical support and psychosocial rehabilitation support (DHS, 2007). It is questionable as to whether privately funded accommodation can offer adequate levels of support to people with mental health problems on statutory incomes. Again, it is often families and carers who provide additional financial, practical and emotional support.

2.3 Homelessness and mental health

The system of services for homeless people is also complex. Services are designed to provide crisis accommodation or transitional accommodation to assist residents to stabilise their housing and learn necessary skills while they wait for longer term social housing.

The relationship between mental illness and homelessness is a close and complex one. Evidence suggests that people with mental illness are more likely to be homeless and, likewise, 53% of homeless persons develop mental illness after becoming homeless (Chamberlain et al. 2007).
Stable, long term housing has been shown to be an essential pre-requisite to recovery from mental illness (Rosenfeld, 1990, Baker and Douglas, 1990) and, conversely, treatment and support has been shown to reduce the likelihood of people with mental illness becoming homeless.

The lack of long term housing and support options for people with mental health problems results in the blockage of crisis housing and transitional accommodation and adds to access problems and inefficiencies. Few homeless or transitional housing services are resourced adequately to support those with mental illness.

As stated by Carter et al (2008), “Of all the factors that have contributed to the increase in the number of people who are homeless in Australia, shortcomings in the delivery of services to people with mental illness are among the most visible in the current policy environment”.

3. **A more systemic approach**

As described above, people with mental health problems often need to negotiate and access multiple service systems to meet their needs for housing, treatment and support. The accommodation, mental health treatment and support needs of people with mental illness are inseparable and interdependent. But the service system is structured to meet needs separately. The provision of suitable, stable housing must be a cornerstone of meeting the needs of people with mental illness. Housing system failure for this client group guarantees mental health system failure and vice-versa.

Government structures have separate jurisdictions with sometimes unaligned priorities to deal with housing and mental health services. A recent Commonwealth example of this occurred in 2006 when $1.9 billion was allocated to new mental health programs without any additional allocation or targeting of housing for people with mental illness (Council of Australian Governments 2006).

Although the costs of providing housing and support may be viewed as being high, the cost benefits of doing so are considerable. Studies from Australia (Flateau et al, 2008) and overseas (Mondello, M. 2007), show that the provision of housing and support programs for people with a mental illness can dramatically reduce costs in the following areas:

- Incidence and duration of hospital admission
- Homelessness services
- General health services, including accident and emergency departments
- Alcohol and drug treatment and support services
- Prison services

When these ‘cost-offsets’ are taken into account, the studies show that the costs to the tax payer of providing housing and support can be minimal, approaching cost neutrality. A cross-departmental or whole of government approach is required to take advantage of these cost-benefits.

4. **Which models of housing and support work?**

A number of existing models of housing and support have been shown to be successful and effective (O’Brien et al 2002). In Victoria, the Housing and Support Program (HASP) was established in 1992 to support people with psychiatric disabilities. Project 300 was set up in Queensland in 1995 and the Housing and Support Initiative (HASI) in NSW was started in 2002. All three programs have the following components in common:

1. Long term, secure housing (through public or community housing)
2. A supportive landlord (community housing provider, separate from the support provider)
3. Clinical support
4. Psychosocial rehabilitation or disability support

Carers Victoria : Submission to the Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness 20
5. A "joined up approach" to achieve a high level of co-ordination and co-operation between the above elements.

Program evaluations for Project 300 and HASI have demonstrated effectiveness in:

- Enabling clients to remain living in their own homes
- Increasing independence
- Assisting clients to be more able to recognize and manage symptoms. This leads to a reduction in the amount of non-clinical and clinical support needed and reduction in hospital admissions. (Robson 1995, Muir et al 2007, Meehan et al 2007)

HASI's evaluation also showed that clients had improved community participation, access to health services and improved family connectedness. The program has been shown to be cost effective.

Program differences between different states are informative. In Victoria and NSW, support is provided by workers and services that have an explicit psychiatric rehabilitation focus and expertise, whereas in Queensland (Meehan et al 2007), support is provided by disability workers and agencies that do not have a specialized mental health focus. Comparison of evidence suggests that while Project 300 clients in Queensland experienced favorable outcomes in terms of maintaining their housing and reducing hospital admissions, social inclusion outcomes such as community and workforce participation were less favorable.

In all programs, a high proportion of participants reported that loneliness was a problem. Given that loneliness and social isolation are strongly correlated with a number of adverse health outcomes, it is important that service design and practice adapts to this finding. One experienced practitioner's suggestion was that while it is important to many program participants that they live by themselves, there may be significant social benefits to be had by these homes being in close geographical proximity to each other.

Housing options for people with a mental illness must be based on client choice. Work done in the USA by Dr Tsberis has developed an evidence based "Housing First" philosophy for homeless people with mental health and substance use problems. It maintains consumer choice at the heart of service design and practice (Tsberis 2000). He argues that respecting client choice results in success and, conversely, the opposite is true.

This approach, if followed, resolves a good number of other decisions such as where someone should live, with whom, how much support they need and so on. Tsberis argues that people with mental illness, like the rest of us, need homes (not "services") that are affordable, of good quality, feel safe, are shared or not shared with people of our choosing, and are located near essential services, transport, family and friends.

5. Recommendations

5.1 The development of data systems that adequately measure the housing needs of people with mental illness is essential. It is hoped that governance and accountability reforms through the Victorian Government's Mental Health Reform Strategy will address this problem.

5.2 Research into the specific experiences and needs of ageing parent carers of people with mental illness which consider the future needs of their sons and daughters for supported housing and ongoing psychosocial support.

5.3 Increased investment in appropriate affordable long term community housing for people with a mental illness through housing associations, with the support of specific mental health housing allocations and targets.
5.4 Investment in the development of a more complete continuum of support for people with mental illness. Expansion of Integrated Rehabilitation and Recovery Care Service (IRRCS) program, Intensive Home Based Outreach Services (IHBOs) and Home Based Outreach Services (HBOS) is essential. This expansion would be based on an examination of, and response to, critical areas of service gap where higher levels of support are required.

5.5 Future housing development and design for people with a mental illness must apply learning drawn from the evidence base of providing effective housing and support programs.

5.6 Further regulation of pension-level and above pension-level Supported Residential Services is required to ensure appropriate standards of care and support, with adequate resources to implement and support changes.
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