



**PARLIAMENTARY INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR MENTAL ILLNESS**

**SUBMISSION BY
THE VICTORIAN COALITION OF
ACQUIRED BRAIN INJURY SERVICE PROVIDERS (VCASP)**

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BACKGROUND

Victorian Coalition of ABI Service Providers

The Victorian Coalition of ABI Service Providers (VCASP) was established in 1998 in response to a need for coordinated policy and service development for people affected by acquired brain injury (ABI). VCASP acts as a peak body for public and private sector service providers who assist people with acquired brain injuries, their families and others involved in their support. VCASP advocates for the availability of appropriate services and resources, as well as information and research that can assist those experiencing the effects of ABI.

Acquired Brain Injury

Definition: injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. These impairments can be temporary or permanent. ABI can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke.

The effects of ABI on an individual can be significant and life-changing, resulting in a need for lifetime care. A person with ABI can experience a range of physical and psychosocial impairments presenting as multiple, complex and severe disabilities. People may require assistance with everyday activities including bathing, toileting, dressing and eating. Along with physical problems, emotional control and memory problems a person with an ABI may have problems with:

- impulse control – they may say and do inappropriate things without thinking
- initiation – difficulty generating ideas, making plans and following through
- lack of insight – they may deny having any significant problem, have minimal awareness of the impact of their ABI on daily life and future plans, and have reduced awareness of their impact on others.

Changes to a person's behaviour are very common after ABI and range from subtle changes, such as talking too much, to markedly altered behaviour, such as verbal and/or physical aggression. Challenging behaviour is usually the result of a combination of factors that relate to an individual's brain injury, their environment and personal factors. Often those closest to the person with ABI bear the brunt of their anger and frustration.

Current context

In the last decade there has been a shift in government policy away from expanding supported accommodation to individualised support within family homes. Increasing the range of service models and supporting the option for people to live in their own home is a positive development and is welcomed by the sector. However this policy shift has not been matched by capital investment in suitable housing stock. Office of Housing Policy since 2006 (exclusion of Class 3 buildings from growth funds, changed target groups) has effectively led to a significant reduction in investment in housing suitable for people with disabilities, particularly people with high support needs. Furthermore, the lack of development in a suitable range of supported accommodation options has disadvantaged adolescents and adults with moderate to profound disabilities who require significant levels of support to maintain life in the

community and for whom supported accommodation outside the family home is a preferred option.

RESPONSE TO THE INQUIRY

VCASP welcomes the opportunity to provide input to the Family and Community Development Committee Inquiry into Supported Accommodation for People with a Disability or Mental Illness (the Inquiry). A number of VCASP member organisations have also made their own submissions to the Inquiry.

Issues raised in the Inquiry Discussion Paper

Availability, suitability

The **chronic shortage of affordable supported accommodation** is well recognised. The Auditor General's Report on supported accommodation 2007 notes that:

"DHS is unable to provide support for all those requesting it (unmet demand is around 1,370 people or 30 per cent), yet demand is increasing by around 4 to 5 per cent annually and DHS has not accurately quantified future support needs or the associated need for resources."

In addition to the serious shortfall there is a **limited range of options** to meet the needs of Victorians with a disability who require supported accommodation. People who have an ABI often experience particular difficulties accessing appropriate accommodation. As outlined above people who have experienced an ABI have diverse and often complex support needs, which may include behaviours of concern. The options that currently exist are often not suitable for people with complex needs. *For people with a dual diagnosis of ABI and mental illness* there are no adequate options. People with ABI and mental illness need accommodation with staff skilled in ABI and mental health who can manage challenging behaviour. Some people may also need secure accommodation.

Implications of insufficient supported accommodation / limited range of suitable options

The severe shortage of accommodation and limited range of options results in crisis driven responses, placement of people in inappropriate options and significant distress for many individuals and families. Many people with ABI end up in highly unsuitable accommodation following their injury. This includes:

Hospital

- Many people who have an ABI remain in hospital after their injury for considerably longer than is medically necessary because there are no suitable accommodation options available. This obviously results in significant costs to the acute health system.

The lack of appropriate community based accommodation for people with a dual diagnosis of ABI and mental illness results in people with ABI and mental illness remaining in totally unsuitable settings for lengthy periods. For example, many individuals who are admitted to the Royal Talbot Rehabilitation Centre - Brain Disorders Unit (Mary Guthrie House) cannot exit the program as there is no accommodation for them to move into. Because people have "a roof over their

head” (albeit a hospital roof) they are not given priority for supported accommodation or individual support packages.

Examples:

X is a 56 year old man with a dual disability of ABI and Bi-Polar Disorder. He is wheelchair dependent and hearing impaired. He desperately wants to have a home and often laments to staff about his situation. He has been an inpatient for over 7 years and he no longer needs the services available on the specialised rehabilitation unit on which he remains living. He has been listed on DHS Disability Services Register for six years as requiring recurrent funding and supported accommodation in the community. Unfortunately X is over 50 and therefore was not included in the My Future My Choice Initiative. X needs a small group home which is wheel chair accessible with staff who are skilled in understanding both mental illness and ABI and 1:1 support to assist him to go out into the community.

Y is a 31 year old man who prior to his injury worked as carpenter. He has a non-compensable ABI as a result he is frequently confused and disoriented. He has resided at Mary Guthrie House (MGH) for the past five years. Due to his ABI Y finds noise and people coming into his personal space very difficult to tolerate. Whilst Y has been ready for discharge for two years and is listed as requiring supported accommodation with DHS Disability Services no accommodation has been offered to date. Y's behaviour and mood are considerably better when he is not on the crowded and noisy hospital unit and when he can be occupied in activities. He no longer needs the services available on the specialised rehabilitation unit on which he remains living; he would benefit more from a continued program of rehabilitation in a community setting. Y would do very well in a small supported group home from which he could not wander with staff skilled in working with people with ABI. Residents in Y's section of MGH are excluded from the My Future My Choice Initiative because of funding boundaries.

For further examples see Appendix A.

Residential aged care (RAC)

58% of the participants in the *my future my choice* initiative (targeted at people under 50 living in RAC) have an ABI. While there is considerable progress in developing new options, the needs of many of the people covered by the *my future my choice* initiative remain a long way from being met. The planned alternatives currently ‘on the drawing board’ or under construction will still leave approximately 40% of the people who said they would like to move to alternative accommodation / support options with no immediate or even medium term hope of having their wishes fulfilled.

Criminal justice system

Recent work by Corrections Victoria in conjunction with arbias indicates that 60 – 70% of people in correctional facilities in Victoria have an ABI. It seems that this is becoming a de facto accommodation service for many people with an ABI.

Other congregate care

Often people with high needs are aggregated into groups setting such as Community Residential Units (CRU). This is to deliver economies of scale and critical mass for service provision not because of a natural desire of people with a disability to live in a group setting. People living in such settings have very little, if any, say about who they live with and the likelihood of incompatible co-residents is high, particularly in the crisis-driven system that currently exists.

People with ABI often don't see themselves as disabled, and may be strongly opposed to living in accommodation in congregate settings with other people with disabilities. In addition, ABI often results in difficulty / inability to live with others

therefore congregate solutions may be particularly unsuitable for some people with an ABI. Supported accommodation where people have their own individual units is likely to be a more suitable option for many people with disabilities, including people with an ABI.

Supported Residential Services (SRS) - people are often compelled to use SRS as they are the only option available. SRS accommodation does not provide the level of personal care or behaviour assistance that many clients require. Many SRS staff have very limited understanding of, and ability to appropriately support, people who display behaviours of concern.

Often the SRS accommodate large numbers of people and staffing ratios are inadequate for the number of residents. Further, many vulnerable people meet and mix with others who may be involved in substance use and abuse or criminal activity. Anecdotally, there are numerous instances of assaults, property damage and theft. All SRS require significant contributions from residents, which then leaves minimal funds for personal spending.

Some private SRS have specialised in working with particular groups of people for example people with ABI. This has been more successful because there has been a semi-formal partnership with the ABI sector and therefore additional supports (case management, secondary consultation and social/recreation funding) are available.

The accommodation shortage is so critical that some people are forced into *makeshift arrangements such as boarding houses, motels or caravan parks*. While this sort of accommodation may work for a small number of people, for most it does not provide the stability, services or support required, particularly with regard to consistent management of behaviours of concern.

Own home / with family

A significant number of people with an ABI have returned to live with family carers after their injuries. They may live with parents (many of whom are ageing) or have spouses, children and siblings who are in the carer roles. For many this is a very suitable option, or would be if they and their family received adequate support (usually not the case, particularly for people who do not have compensation). However some people live with family because they cannot find suitable supported accommodation in the community, creating considerable stress both for them and the family members providing their support.

The highest number of people who have an ABI are young men who acquired their brain injury when aged between 15 and 25. Many of these remain in / return from independent living to parental homes, often for many decades. Young people who had every expectation of normal life stages suddenly find themselves with few / no options but to remain dependent on their parents. Parents who had every expectation of normal progression to a time when their children live independently find themselves facing the prospect of a lifetime caring role for their adult child. There are significant long-term social costs associated with forcing younger people with a disability and their families into living situations not of their choice and inappropriate to their stage of life.

Respite

Access to out-of-home respite may be a critical factor for people living at home in sustaining their living situation and supporting their family members to maintain their role as carers. Access to respite is becoming increasingly difficult, in part due to the chronic shortage of long-term supported accommodation, which has meant that many respite places have become de facto long-term placements for people in urgent situations whose families are no longer able to support them at home. The shortage has, in fact, forced some families into the desperate measure of refusing to take their disabled family member home from respite placement because they can see no other solution.

People with acquired brain injury are often denied access to respite facilities. This may be because they are not attending a day program and therefore require 24 hour support (many disability respite facilities expect residents to be at day programs on weekdays) or because their physical and/or medical or behavioural support needs are perceived to be too high for the facility to manage. Some people are able to access respite through residential aged care or acute hospital beds, both highly inappropriate and expensive options.

Adequacy of care

Current funding models for supported accommodation only allow for the housing component and for meeting basic needs. In some options even basic needs are not adequately met and people with cognitive support needs tend to be particularly disadvantaged by this under-resourcing. Most people in supported accommodation do not have the quality of life they should expect as Victorian citizens.

The quality of care can vary from house to house and service provider to service provider and is in part dependent on the skill sets of the staff and the level of support and supervision. This is especially evident when working with people with complex and/or specialist needs such as people with ABI. There are critical workforce issues across the sector with major difficulties in recruiting, training and supporting staff. The common base qualification for disability support staff is Certificate IV (Disability) but this does not adequately prepare people for employment in residential services. This course can be a useful introduction to disability work however it does very little to foster appropriate attitudes towards and understanding of people with disability. It certainly does not provide adequate knowledge of the specific needs of people with and ABI nor enough depth to enable workers to grow and positively challenge their work practice.

Information, planning and decision making

The demand management system has moved from the Service Needs Register (SNR), which allowed for registration of future need and therefore had some capacity for forward planning, to the Disability Support Register (DSR) which only allows for registration and prioritisation of immediate need. Even with this limitation of eligibility, the system cannot respond to immediate / urgent need and, as the Auditor General's report highlighted, remains crisis driven.

Crisis responses lead to:

- incompatible groupings of residents

- poor / non-existent transition planning with consequent disruption, distress and adjustment difficulties.

The experience of VCASP members is that the DSR process lacks transparency and independence of decision making. There are inconsistencies between regions and, despite the new Disability Act, there are still instances of people with ABI being told they are not eligible for DHS-funded disability services.

The decision to register an applicant on the DSR rests with Disability Client Services. This includes the recommendation for Priority Status. People with disabilities, their families and service providers are advised that a person has been accepted onto the DSR but are not advised if they have been determined as having priority status. This leaves no mechanism to appeal this decision.

It is extremely difficult for families to gain access to the supported accommodation system. People may be listed on the DSR for many months and even years waiting for an individual support package or a shared supported accommodation placement. The demand management strategy through the DSR puts up multiple barriers and many people simply give up. VCASP member organisations attempt to support families by assisting them to complete the necessary documentation whilst also providing emotional support and interim support even though they are not funded to do this.

The decision making process for allocation of services is not transparent. No information is provided about the skills of panel members or the timing of panel meetings. People do not know when they are being considered for a vacancy, which means if an offer is made following the panel they have very little time to consider the suitability of the place being offered.

Because of the critical shortage of supported accommodation priority is not given to people wishing to move from inappropriate, more restrictive living situations such as Supported Residential Services, Residential Aged Care (over 50's) or 'makeshift' living situations such as motels, caravans etc.

Required Action

Over-arching issues

- A ***whole of Government approach*** for accommodating people with a disability needs to be developed across all departments, authorities, divisions and regions linking with and ensuring consistency with existing standards.
- Victoria needs to substantially increase its stock of ***universally designed housing*** (both social and private housing) as quickly as possible. Introduction of universal housing regulations would seem the best way of achieving this.
- There is clearly a need for a ***range of options*** as no one model will fit the needs and aspirations of all people. However, it is equally ***important to ensure that choices made today do not lock in a lack of choice for others in the future.*** For example, large scale congregate care models absorb a significant amount of

the available resources and tie up future resources in an inflexible model that allows little scope for alternative developments. Smaller, more flexible arrangements that can be adapted to other uses or ways of operating allow more scope for the range of options required to meet differing needs.

- Long-term planning and development of options must have ***involvement of all stakeholders*** including people with ABI and families. Choice and flexibility can only be achieved by planning in partnership with those who are needing supported accommodation and, where appropriate, their families / carers and other supporters. Choice will not be achieved by developing models and expecting people to fit into them.
- The approach to developing new services should be ***informed by research and knowledge*** of what works / doesn't work here in Victoria, elsewhere in Australia and overseas. There are a number of positive models currently available that could be examined to understand why they work, how they can be replicated and for whom they would be appropriate.
- ***A co-ordinated system for housing and support package funding and allocation*** is critical. There are, unfortunately, many instances of people being unable to take up housing when it became available because funding for support services is not available, or conversely not able to take up community based support options because accessible housing is not available.
- The approach to the provision of support needs to be ***tailored to the particular users*** of the service. People with an ABI require a rehabilitation focus to enable them to continue to make gains in their recovery.
- A commitment to deliver ***high quality of life outcomes*** should underpin development of support and accommodation for people with a disability. This requires a person-centred approach with services designed around individuals, supporting their lifestyle choices and culture.
- Changed living arrangements will be more appropriate and successful if they are planned in advance with the individual and their supporters (e.g. family, friends, local community supports, service providers) and prepared for through ***effective transition processes***. It is very difficult for people to make informed choices if they have insufficient information about and experience of possible options. The system needs to include possibilities to trial options and develop skills in transitional settings.
- ***Appropriate use of aids and technology*** may, in some cases, reduce the need for 'people support' and can help to prevent health problems and provide more security, e.g. mattresses/beds that lessen the need for regular turning, personal alarm systems, environmental control units, memory aids.

The range of models should include:

- *support to live in own home* - this is an existing model however there are many people wanting this sort of support who are not able to access it given current

funding levels. The model also needs to be enhanced so that it can cater for people with high support needs. People with the highest levels of need can live independently if they have enough support, as illustrated by Transport Accident Commission (TAC) claimants. A possible model for a high level home support package is attached – see Appendix B.

- schemes that enable the option of *individuals / families contributing or managing the housing* (either self-funded or through provision of low-interest loans or rental of public housing) with government providing adequate support packages. Where families provide financial resources to assist in the provision of housing and support, the arrangement needs to be simple, clear and equitable. Family or individual contributions (or the lack thereof) should not affect their access to a Government funded or provided service.
- *shared arrangements* - families are not always able to provide full-time care, but many would choose to participate in support for their family member to their capacity. An all-or-nothing approach to re-housing often denies families the opportunity to contribute as fully as possible to support arrangements. This is to everyone's detriment. Providing some elements of shared care between family and other appropriate accommodation settings would be useful.
- *individual options with shared support* - as discussed above supported accommodation where people have their own individual units is likely to be a more suitable option for many people with disabilities, including people with an ABI. While not everyone will need 24 hour support there are many people who require this level of support. Options offering 24 hour support must be part of the continuum of accommodation support.

Examples of this sort of accommodation include:

- St Martin's Court (operated by Australian Home Care Services) which provides independent living units for people with an ABI and other neurological disorders who require assistance and supervision with planning, decision making, safety in the community and more complex activities of daily living such as cooking and shopping. This facility also has 2 units providing respite accommodation.
- Healthscope facility which provides a shared main house as well as individual units at the back.

In shared supported accommodation where it is not possible to provide individual units, the design must allow for maximum privacy and individual space.

- *interim residential care with a specialist slow stream rehabilitation focus* - such an option is a crucial service in the suite of residential and rehabilitation options to cater for the needs of a growing number of Victorians with ABI who are not eligible for acute rehabilitation support, providing them with the opportunity for recovery after 'catastrophic' injuries at a slower pace.

People with highly specialised needs

- *People with high physical / medical / communication needs*
Some people with ABI have severe physical and sensory disabilities

combined with high health care needs. They require twenty-four hour specialised nursing, specialised therapy and appropriate medical oversight. They have an extremely narrow margin of health and this puts them at serious risk in any environment that is not fully responsive and attuned to their clinical, therapeutic and support needs. Close attention is necessary to the individual communication means of people without speech to ensure their needs are understood and responded to. Supported accommodation that provides the required physical environment, specialised staffing and socio-medical support model is essential for this group.

- *People with complex needs associated with mental illness and ABI*
For people with complex needs associated with mental illness and ABI both Disability and Mental Health Services will be required to support their accommodation placement and on-going life in the community. There is a need for collaborative work between Disability Services and Mental Health Services to develop suitable accommodation for this group of clients.

Features of such accommodation would include:

- Higher level of staffing than is currently available in most community settings. Individuals with complex needs associated with ABI and mental illness often require supervision and frequent redirection for successful management. The staffing needs to be tailored to the needs of the particular residents and should allow for provision of adequate supervision, management of behavioural difficulties and individual attention when necessary.
- Staffing to enable supervision and individual support during the day. Most CRUs and SRSs rely on their residents going to day programs during the day however people with ABI and chronic mental illness cannot always sustain this.
- Staff trained in managing complex clients. Such training should include ABI, mental health, and behaviour management.
- Capacity to offer a secure environment. Some individuals with ABI / mental illness may require a secure environment due to their poor safety awareness, confusion or the likelihood they may place themselves at risk.
- A physical environment that is accessible and safe for people who have mobility impairment.

Good accommodation services for people with ABI

The most successful services are those that have been set up specifically for people with an ABI. One of the most important factors in success is staff having specific training in working with people with ABI. Examples of good practice in the provision of accommodation services for people with an ABI are outlined in a report completed by VCASP in 2007. This report is attached as Appendix C.

Community / private / government sector management

Both DHS and NGO's support people with varying needs yet in 2006, the non government sector was funded at an average rate of \$68,545 per person and the government sector was funded at a rate of \$92,460 per person in 2006, a differential of more than 25%. In addition DHS managed services have received a far greater allocation of capital funds over the past four years. Many of the innovations in

accommodation and support have emanated from the non-government sector and, in the main, the non-government sector provides very good services. However NGOs are struggling to retain staff and maintain quality service given this funding differential. There is need for greater investment in the non-government sector to maintain the broadest possible range of services and support innovative practice.

Private providers can be a positive influence in development of options. They have developed specialist options for the compensable sector which can have benefits for the non-compensable sector both in terms of learning and also extension of services through purchase of places by Disability Services Division for people who do not have compensation. However community sector organisations have experienced some issues with accountability of this sector, e.g. private sector agencies are sometimes resistant to 'intrusion' of community sector workers, such as case managers.

Importance of an integrated system

Wasteful and inefficient anomalies can occur when service systems are not well integrated. For example, people with an ABI include those in receipt of compensation (in Victoria through the Transport Accident Commission or the Victorian WorkCover Authority), and those without compensation. This has often resulted in accommodation options being created only for those with compensation funding, leaving people who are dependent on the public system with few/no options. In less populous country regions in particular this has sometimes led to accommodation facilities struggling for viability, i.e. unfilled vacancies because there are not enough people in the area who have compensation funding, while at the same time there are people who do not have compensation funding who are desperately in need of accommodation, may well be compatible with the other residents, but are unable to access the local option because they do not meet the eligibility criteria. Solutions in local areas need to be co-ordinated and flexible to meet the needs of often small numbers.

Funding

It is essential that there is acknowledgment of the real costs of ensuring full participation of people with disabilities in the life of the community. While it is recognised that governments have finite resources it is unacceptable that many people with disabilities are still without even the most basic support services and suitable housing. There is an urgent need for joint Commonwealth and State Government action to extend the funding base for disability services. VCASP supports the work currently underway in relation to a national disability insurance scheme and urges continued commitment to ensure adequate funding for disability housing and support.

Specific populations

Regional and rural Victoria – Many people with an ABI may move to Melbourne for specialist services however this may lead to loss of community connection and family involvement. The provision of supported accommodation should be available to people in their local communities to enable them to maintain their support networks.

Culturally and linguistically diverse backgrounds – Services must have the capacity to respond to diversity of needs. This may require additional funding, e.g. for staff training, costs associated with providing information and support in appropriate formats for example translation services and interpreters.

Indigenous Victorians - This group tends to be under represented in disability services so a targeted strategy based on consultation with indigenous Victorians seems appropriate. There is a case for both indigenous-specific services and generic services. Services need to establish links with key community members to assist with planning and development of appropriate models of service delivery. Time and resources to connect and develop relationships with indigenous communities are vital to the provision of successful supports.

CONCLUSION

In order to achieve the vision outlined in the State Disability Plan we need to have a supported accommodation system which is not crisis driven and able to provide a planned approach to a range of real and safe options for people with disabilities and complex needs. It should be innovative and designed to promote quality of life for people with disabilities. A viable system must be based on a sustainable workforce capacity and represent best value in the use of public funds.