AUSTRALIAN GOVERNMENT

DEVELOPING A NATIONAL DISABILITY STRATEGY FOR AUSTRALIA

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

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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.

A person with ABI can experience a range of physical and psychosocial impairments presenting as multiple, complex and severe disabilities. 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.

The effects of ABI on an individual can be significant and life-changing, resulting in a need for lifetime support. People may require:

- assistance with physical activities including bathing, toileting, dressing and eating
- cognitive support – memory aids, prompting, assistance with decision-making, organising, etc.
- behaviour support, particularly with aggressive or violent behaviour and behaviour that is harmful to self and/or others.

Introduction

VCASP welcomes the commitment by the Australian government to achieve better outcomes for people with a disability and their families through development of a National Disability Strategy and endorses the decision to base the Strategy on the *UN Convention on the Rights of Persons with Disabilities*.

For the strategy to make a real difference to the lives of people with a disability it must encompass all factors affecting the right of people living with disability to be included and participate equally in all aspects of the community. It must directly address the causes of systemic discrimination and commit to specific actions. The National Disability Strategy should contain clear actions and expected outcomes in all major areas of public life (work, leisure, transport, housing, built environment, civic participation, education etc), measured against the principles within the UN Convention.

While people with a disability share concerns in common, VCASP believes that a National Disability Strategy must also reflect the needs and experiences of people with specific disabilities. The experience of VCASP members is that community awareness of ABI significantly lags behind that of other disabilities. People with ABI and their supporters consistently report that the lack of community awareness in the broadest sense (i.e. inclusive of government, service providers, community organisations, employers etc.) is the single greatest obstacle to full participation. The cognitive-behavioural challenges that many people with an ABI experience discourage them from social participation precisely because those challenges are not understood as being a function of their disability. Outright exclusion is the commonest consequence.

Our submission addresses issues affecting people with disabilities generally with emphasis on those areas that impact most significantly on people with an ABI.

Community awareness

The National Disability Strategy must include a genuine commitment to national level awareness-raising across all disabilities including acquired brain injury.

Education

Children / young people with ABI have particular difficulties in the education system because cognitive disability, and ABI in particular, is often not recognised or included as a criteria enabling access to specialist support. Definitions of disability should be standardised across all States and Territories to include the category “Cognitive Disability” as being eligible for Australian Government-funded programs for students with disabilities and that category should specifically include “Acquired Brain Injury” by name.

IQ tests have been shown to fail to pick up the specific neurobehavioural areas that are particularly vulnerable to the impact of ABI, for example, attention, speed of processing, memory and learning. Moreover, they often place the performance of students with an ABI within normal limits, despite the presence of ‘significant processing and learning disorders’. Comprehensive neuropsychological assessments of students with an ABI should be made

available in a timely way across all State and Territory educational jurisdictions and to both government and non-government education providers.

Community infrastructure

Accessible community infrastructure should be considered as a priority area in relation to the National Infrastructure Fund and other initiatives of the Australian government – this would bring both economic and social benefits to the Australian community. This includes public space and buildings, housing and transport. Housing is a significant area of disadvantage that needs attention:

Housing

If people with disabilities are to fully participate in community life then they must not only live in a house that meets their access needs but they must also be able to visit family, friends and neighbours. This requires that we develop policy around universal housing design for both public and future private housing.

A paper by the Queensland Department of Housing (June 2000) defines universal housing design as follows:

> *Universal design translates as sensible design, which is useful and marketable to people with diverse abilities, and hence, aims to meet everyone's needs and avoids discrimination against any users. Universal design makes as little as possible exceptional and as much as possible standard.*
>
> *Universal design aims for minimal adaptation over time to meet changing need...*

In practical terms this means housing that includes basic access features such as step free entry, wide corridors and doorways, and a toilet/shower that can be easily adapted for use by someone with a disability. For cognitive injury, examples of access would include transparent cupboard door and built-in labelling options in the home are essential memory prompts to assist people to be independent.

Access to support

People with disabilities are entitled to the same opportunities as others for a quality life in the community. All people in our society use a range of funded and unfunded infrastructure and direct supports. People with disabilities may require additional supports to enable them to attain a quality of life commensurate with others in the community. If people with disabilities require support to do, or be involved in, ordinary activities that other people do without support then this should be available at no cost. This includes physical, cognitive and behavioural support.

VCASP supports the concept of individualised funding which is about:

- people with disabilities getting funding based on their individual needs
- having control over how this funding is used. This means having the flexibility to meet their support needs in the way that best suits them, the choice to directly employ their own support workers or to purchase their support services through an agency of their

choice. This could be through the use of mainstream community services, negotiating with specialist services to tailor their services to individual needs or creating new services and supports if required.

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. Individualised funding packages should allow for both 'people' and 'equipment' support.

Support for carers
Many people with disabilities continue to depend on family carers as their primary source of support. Family carers need adequate support from governments to enable them to support people with a disability to live a full life and to maintain their own physical and mental health and wellbeing.

Supported accommodation

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. The options that currently exist are often not suitable for people with complex needs. 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.

- *Residential aged care (RAC)* – in Victoria 58% of the participants in the Young People in Residential Aged Care initiative have an ABI. While there is progress in developing new options, the needs of many of the people targeted by this initiative remain a long way from being met. Many young people with high support needs remain in / continue to be admitted to residential aged care. There is need for intensified effort to develop suitable support and accommodation options for this cohort.

- *Criminal justice system* - recent work commissioned by Corrections Victoria 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). 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.

  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.

- The accommodation shortage is so critical that some people are forced into *unsuitable / makeshift arrangements* such as Supported Residential Services (SRS), boarding houses, motels or caravan parks. For most people these options do not provide the stability, services or support required, particularly for those people who require support to manage behaviour.
- *Own home / with family* - a significant number of people with a disability remain living / return 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. 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.

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 citizens.

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. 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.

A commitment to deliver *high quality of life outcomes* should underpin development of support and accommodation for people with a disability. Long-term planning and development of options must have *involvement of all stakeholders* including people with disability and their supporters. The approach to developing new services should be *informed by research and knowledge* of what works / doesn't work in Australia and overseas.

Funding base

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 strongly supports the introduction of a *national universal disability insurance* scheme that provides disability support to Australian citizens with disability regardless of the cause or origin of disability.

Workforce Issues

It has become increasingly difficult to recruit and retain quality workers to provide support for people to live their daily lives. This results in gaps in support provision (unfilled shifts), workers being rostered to work without adequate training, constant demand on users to train new staff in their specific support needs. This impacts particularly severely on people who have high support and/or complex care needs.

The National Disability Strategy should include an extensive review of workforce issues, including casualisation, pay levels, staff support, training and career opportunities with a view to development of work structures that enhance the capacity for individuals with disability and service providers to recruit and retain high quality staff and that develop service delivery structures that are more attuned to the needs and choices of people with disability. This review should be done in collaboration with people with disabilities and the service sector.

Specialist services / supports

Some people will need specialist support to enable the fullest possible participation in community life. VCASP endorses Recommendation 2 of the Senate Standing Committee on Community Affairs inquiry into the "Funding and Operation of the Commonwealth State/Territory Disability Agreement [CSTDA]; namely "that the next CSTDA clearly recognise the complex and interacting needs of, and specialist services required by, people with dual and multiple diagnosis, and people with acquired brain injury". Recognition of the specific needs of people with an ABI needs to be backed up by funding of specialist services, advocacy and training.

One of the specific needs of people with an ABI and other acquired disabilities is the integration of their rehabilitation requirements with other disability supports, to enable them to continue to make gains in their recovery. This includes an overall focus on a rehabilitation approach to service / support provision (as distinct from a developmental approach). For some people, specialised residential rehabilitation services such as *interim residential care with a specialist slow stream rehabilitation focus* is required. Such an integrated option is a crucial service in the suite of residential and rehabilitation options to cater for the needs of a growing number of Australians with ABI who are not eligible for acute rehabilitation support, providing them with the opportunity for recovery after 'catastrophic' injuries at a pace that is manageable and effective. Longer-term financial economies are achieved through this approach, and avoid high-cost restorative approaches that involve behavioural management and inpatient admissions to acute and mental health facilities.

Conclusion

Thank you for the opportunity to contribute to this important policy development process. VCASP welcomes the commitment of the Australian government

to work in partnership with all levels of government and the community sector on these important issues. For more information on any of the issues raised in this submission please contact Cath McNamara, email: policy@vcasp.org.au