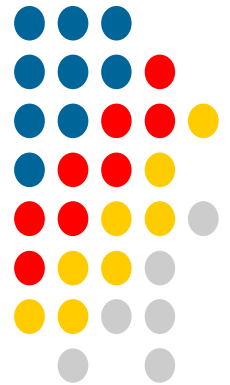


# TASMANIAN COALITION OF BRAIN INJURY SERVICE PROVIDERS (TCASP)

## ‘Neglected, not Forgotten’ Campaign Newsletter No 3

January 2008



This edition of the TCASP Newsletter focuses on the historic neglect of Tasmanians with an acquired brain injury.

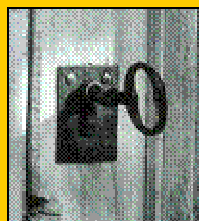
Comparisons are illustrated covering the years 1992 to 2007. What these comparisons clearly show is that little has changed in the provision of support and services to people with ABI by successive Tasmanian governments.

Alarmingly, what ABI service providers were lobbying for in 1998 is very similar to what they lobby for in 2008. This shows a shameful disregard from government towards Tasmanians with ABI.

Remember—it is estimated that each year 2,500 Tasmanians will sustain a brain injury - Less than 2% will receive the supports they need! In light of this startling statistic, the Tasmanian Government has to be proactive in ensuring that all Tasmanians with ABI do receive the supports they need now and have strategies in place for the future. Later in this newsletter the latest statistics from the Australian Institute of Health & Welfare 2007 “*Current and future demand for specialist disability services*” is included, that highlights the projected growth rate of ABI to be at 5.1%.

If you are interested in becoming part of the TCASP Lobby group please phone (03) 6278 7299 to learn how you can also be ‘a voice’ for Tasmanians living with acquired brain injury, many of whom do not receive appropriate supports and services. Indeed many receive no services or supports at all.

## BRAIN INJURY IS FOREVER



PREVENTION IS THE KEY

# The Historic neglect of Tasmanians with Acquired Brain Injury continues

“History repeats itself - has to – nobody listens” Steve Turner

**2007**

The current levels of unmet need reflect chronic under investment by successive governments in the supports and services required to meet the needs of people with acquired brain injury.

(“Neglected not Forgotten” Campaign Newsletter – TCASP **July 07**)

**1991**

“Tasmania is going to go from having one of the worst systems in the nation for assisting people with head injury to one of the best”

(Announcement made by **Premier Michael Field** and **Health Minister John White 1991** – cited in Thompson, K.M 1999 Independent Study B Paper: What is available In Tasmania for people with Acquired Brain Injuries?)

**1992**

“Currently the provision of long term care for people with brain injury.....is grossly inadequate”. The brain injury program will see the development of a state of the art in patient rehabilitation unit to care for the post-acute in-patient rehabilitation of people with traumatically acquired brain injury”

**Health Minister Roger Groom** - Hansard 4 June 1992

“Unfortunately this facility was only operating as a dedicated Head Injury Rehabilitation Unit for a period of twelve months in 1992”.

Thompson K.M 1999

**2001**

“We realise it is an area where we have to do more but it is just a matter of funding”

**Health Minister Judy Jackson** – Wednesday 6 June 2001 Estimates Committee

## So has anything changed?

<p style="text-align: center;"><b>The Cuff Report: A Brain Injury Program for Tasmania</b>  <b>September 1989</b></p>	<p style="text-align: center;"><b>Review of Funded Services for People with Acquired Brain Injury:</b>  <b>Department of Health &amp; Human Services Final Report</b>  <b>August 1999</b></p>	<p style="text-align: center;"><b>Brain Injury Association of Tasmania:</b>  <b>Community Consultation Issues Paper</b>  <b>February 2006</b></p>
<p><b>EDUCATION/TRAINING</b></p>		
<p>Brain injury is a form of disability that is not well understood (p5)</p>	<p>Education and training of generic service providers is non existent or inadequate.            Education of the community about ABI is inadequate (p10)</p>	<p>Tasmanian based organisations and the general public (statewide) have clearly indicated the need for a significant increase in opportunities to access education/training regarding brain injury. (p8)</p>
<p><b>REHABILITATION</b></p>		
<p>Increasing demand together with the differing entitlements that people have to compensation and other financial support will necessitate an effective management system to coordinate service delivery and financial control. (p19)</p>	<p>Not all clients receive adequate rehabilitation, especially non compensable clients. (p10)</p>	<p>In Tasmania there is a significant difference between the rehabilitation opportunities for people who receive compensation and those who rely on either private income or the public healthcare system. (p6)</p>
<p>It is now widely accepted that the rehabilitation process starts during the acute phase in the surgical ward or even in the ICU. In the interests of both the injured person and cost effective service provision, it is essential that rehabilitation services are planned and coordinated. (p13)</p>	<p>The transition from acute care to rehabilitation to community is not smooth for many (p10)  <i>Also noted under Discharge planning:</i>            No continuity of care for clients, no discharge planning for clients, lack of communication between hospitals and the community sector. (p8)</p>	<p>There is a lack of transition support (including formal transition planning from hospital to home).            Many people are not aware of the service models which are available in the community to support them, and need clear guidance and pathways to support them to locate and access the services they need/want. (p6)</p>
<p><b>RURAL ISSUES</b></p>		
<p>Recommendation that a service network of accredited providers, skilled in the rehabilitation of brain injured people be established throughout the state. (p6)</p>	<p>Clients in rural areas have problems accessing services (p11)</p>	<p>Tasmanian residents who live in regional areas (including coastal townships, North and North West) and who acquire a non compensable brain injury and require intensive rehabilitation must relocate or regularly travel to Hobart to gain access to this service. (p6)</p>

<p><b>The Cuff Report: A Brain Injury Program for Tasmania</b> <b>September 1989</b></p>	<p><b>Review Of Funded Services for People with Acquired Brain Injury:</b> <b>Department of Health &amp; Human Services Final Report</b> <b>August 1999</b></p>	<p><b>Brain Injury Association of Tasmania: Community Consultation Issues Paper</b> <b>February 2006</b></p>
<p><b>RESPITE</b></p>		
<p>Respite care facilities are needed urgently for those families, particularly mothers and wives caring for a family member with severe disabilities. (p19)</p>	<p>Funding to be provided for respite to people with ABI across the State (p4). There is not enough respite care available for non compensable clients (p10) Respite for families and carers should be provided (p15)</p>	<p>There is a lack of appropriate respite available for children and adults with ABI. There are limited options available (p10)</p>
<p><b>SERVICE SYSTEM</b></p>		
<p>A network of accessible support services be developed throughout the State (p3)</p>	<p>Disability services (including funded services) work closely with the acute care sector, rehabilitation and other services (such as MAIB) to develop, over time, a more integrated and flexible service system for people with ABI in Tasmania. (p5)</p>	<p>People with ABI in Tasmania urgently require a real Commitment from the Department of Health &amp; Human Services to develop a service system which addresses their current and future needs (p29)</p>
<p><b>SUPPORTED ACCOMMODATION</b></p>		
<p>While there is no current experience to use in identifying the accommodation requirements of the program, it is anticipated that up to 25 newly injured people could require assistance each year. Therefore the provision of cost effective accommodation be recognised as a priority.(p3,18)</p>	<p>Disability Services to consider clients with ABI for placement in any vacancy that that may become available in existing accommodation services provided that the service and support is deemed appropriate. If funding becomes available, Disability Services should also consider the option of establishing a specific group home for people with ABI in Tasmania. (p3)</p> <p><i>*Note: 2 group homes were established for people with acquired brain injury in 2006. One in the North and one in the South of the State.</i></p>	<p>Supported accommodation options within Tasmania for people with ABI is extremely limited. Inappropriate accommodation placements and limited supports commonly result in a loss of contact with services, itinerancy and homelessness. Supported accommodation needs to be viewed as part of the rehabilitation continuum. A significant increase in the availability of accessible housing, individual funded packages and supported home environments for people with acquired brain injury is required.(p15,17)</p>

CASE MANAGEMENT		
<p>The Head Injury Rehabilitation Unit (<i>proposed</i>) to have a team to provide long term support, provide/coordinate services for brain injured people as appropriate such as (attendant care, residential accommodation, aids and appliances, respite care, educational and vocational programs and transportation) (p14)</p>	<p>Funding be made available to provide case management for clients with ABI across the State. Funding to be allocated to Disability Services to engage two case managers who have skills, knowledge and experience in ABI (one based in South and one based in North/North West region). Both case managers will work closely with the ABI service providers (p3)</p> <p><i>*Note: 2 case managers were employed however after a period of...they were assigned to general case management thereby losing their focus of being ABI specific.</i></p>	<p>There was a clear indication (Statewide) of the need for all children and adults with ABI and their families/carers to have access to an effective model of case management support. This appears to be a 'missing link' in the coordination of referrals, planning, rehabilitation, information and support continuum to these families. It is recommended that the State Government provide an effective and efficient case management model which is able to recognise and respond to the needs of the individual and their carers (p21,22)</p>
DAY SUPPORT		
<p>For a more severely disabled person, daily activities might include a range of organised social activities or therapeutic sessions. As Headway is currently organising daily activities at St Johns Park it would be appropriate to encourage and support financially their continuing to develop this program throughout Tasmania. (p19)</p>	<p>Disability services provide additional funding to the existing day support services in the South and North of the State (p3)</p> <p><i>Note*Funding was provided for day support options in the South and North of Tasmania, however, the level of unmet need in this area is still apparent. The Nth West region continues to lobby for funding for Day Support Services.</i></p>	<p>Para 5.6 of the revised final draft of the DHHS Discussion paper 'The Future Role and Operation Of Day Services in Tasmania' (August 2003) states "A significant service gap within disability services currently is the provision of day support to people with ABI". Appropriate, adequately resourced day options services should be available throughout Tasmania to people with ABI (p14)</p>

**An ABI specific Day Option Program in the North West was identified as an unmet need in 1999. This still remains the greatest unmet need for people with an ABI in the North West of Tasmania.** (Headway North West Inc -2003, Response to the recommendations of the review of Acquired Brain Injury Services –A progress report, September 2003))

**"History informs us of past mistakes from which we can learn without repeating them"** William Hastie

## So where does this leave us?

**Prior to 1998** the Motor Accidents Insurance Board (MAIB) provided substantial amounts of funding to the non-government organisations that provided support for people with acquired brain injuries. However, a review of MAIB, in May 1998, identified that some of those funds were being used to meet the needs of people who were not the responsibility of MAIB (non compensable). In addressing this issue, MAIB reduced the level of funding to ABI organisations from 1 July 1998. The Minister for Health & Human Services at that time **agreed to meet the subsequent funding shortfall experienced by these services.** (*The Review of ABI Services in Tasmania – A Progress Report –Disability Services September 2003 p1*)

“Numerous requests since 1999 to discuss and appropriately respond to the funding levels and responsibilities for specialist services for people with acquired brain injury throughout the state as a matter of urgency, have largely gone unheeded. For the past 10 years disability services has stated that ABI is a priority but unfortunately has failed to demonstrate this is in action; choosing to continue operating reactively rather than proactively”. (*Brain Injury Association of Tasmania – Submission to the CSTDA Senate Committee Affairs –Senate Inquiry: Funding and Operations of the CSTDA” 2006 p2*)

**2008** sees specialist brain injury services continuing to lobby and advocate for Tasmanians with acquired brain injury, however this takes scarce and valuable resources away from the very supports these services strive to provide.

As stated in *Headway Support Services (HSS) Acquired Brain Injury Issues paper 2006*; **“Under-funded, discriminated against, ignored and angry”**

- **Waiting lists are out of control and it is causing unacceptable human suffering:** The unmet needs of people with ABI have grown to the point that the specialist ABI service providers in each of the regions are literally swamped with new referrals and are unable to respond and have been forced to turn their backs on the needs of people with ABI in Tasmania.
- **State pays a price for neglect: the result of this neglect has two sides – a human cost and an economic cost:**
  - A significant financial and social cost to the community
  - The absence of an effective service system results in individuals being unable to attain their maximum level of recovery and a significant increase in the long term costs associated with the care and support of an individual with ABI
  - Greater reliance and stress is placed on families who have limited physical, emotional and financial resources resulting in a greater need for respite, support and accommodation services
  - Higher than usual incidence of family breakdown
  - Higher rate of domestic violence, suicide and homelessness
  - Extremely high representation of people with ABI in the criminal justice system, in the vicinity of 40-70%

### **ABI specific service providers are under-funded:**

- “There clearly exists a gross inequity in the funding structures provided for ABI services when compared to similar services within the disability sector. There is no additional allocation in the **2005** budget for people with ABI. *Headway Support Services 2006 Report (Ibid)*
- The total disability budget **2006/2007** was \$117 million dollars, of this just over \$2 million (\$2,307,524 or 1.97%) was allocated to ABI services in Tasmania” *Brain Injury Association of Tasmania – Submission to the CSTDA Senate Committee Affairs –Senate Inquiry: Funding and Operations of the CSTDA (p4)*
- From the \$2 million, \$1.5million is allocated to accommodation support for 12 clients and \$185,000 for day support for 4 clients, leaving only \$600,000 to support transitional support, community rehabilitation, outreach services, day support, information and referral and community education.

### **A whole of Government Strategic Plan for ABI is needed:**

- Considering that an acquired brain injury may affect an individual on many levels including; education, employment (greater risk of poverty), housing (sometimes resulting in homelessness), mental health issues, abuse of alcohol and other substances, an increased risk of suicide (3-4 times greater than the population without an ABI), greater risk of entering the criminal justice system, family breakdown and social difficulties, TCASP believe that a whole of government strategic plan is warranted such as the one implemented by the Victorian Government. In 2001 the Victorian Government developed the Acquired Brain Injury Strategic Plan, setting the future direction of policy and service development for people with ABI. One outcome of the strategic plan has been the development of a protocol to enhance service delivery and coordination to people with ABI (*AIHW Bulletin 55 – December 2007*)
- An effective service system response that crosses all Government departments will do much to alleviate the current ad-hoc, poorly resourced, inequitable and discriminatory system that fails many Tasmanians with ABI.
- An inter/across agency approach coupled with greater collaboration between key stakeholders would serve to reduce the human and financial cost associated with ABI. If outcomes for people with ABI are to improve, significant change must occur at the policy, program and service delivery level. People with ABI in Tasmanian urgently require a real commitment from the Tasmanian Government to develop a service system which addresses their current and future needs. ( Brain Injury Association of Tasmanian, Issues paper Ibid 2006, p31)

**“History, in brief, is an analysis of the past in order that we may understand the present and guide our conduct into the future”. Sidney E. Mead**

## What is the future? Australian Health & Welfare (AIHW) statistics

Noted in the *Brain Injury Australia (BIA) submission to the Senate Community Affairs Reference Committee August 2006* (pp 5,6):

“The AIHW analysis of the 2003 ABS Survey of Disability, Ageing and Carers, prevalence estimates for 2003 were:

- 432,700 people (2.2% of the Australian population) had ABI and some activity limitations or participation restrictions.
- 157,500 (0.8% of the Australian population) had ABI and a ‘severe or profound core activity limitation’ – ie: needed help with self-care, mobility or communication.
- 28,700 people said that ABI was their main disability condition
- 90% of people said their ABI main condition was caused by accident or injury
- When compared with all disability groups, people with ABI are far more likely to have multiple conditions including mental health problems and substance abuse.
- ABI disproportionately affects males, with young men having the highest risk of sustaining a traumatic brain injury

According to AIHW’s 2007 Report, *Current and future demand for specialist disability services*:

- **The projected growth** in the numbers of people aged 0-64 years with physical/diverse disability (6.0%) and **ABI (5.1%) is higher than the general rate** in severe or profound core activity limitations in this age group-48% (p91)
- Among people aged 0-64 years the projected population of males is higher than females for the intellectual, sensory/speech and ABI disability groups (p91)
- Among people aged 0-64 years, the broad disability groups with **the highest projected growth rates are** physical/diverse disability (6%) and **ABI (5%)**, the lowest, intellectual disability (1.8%) (p108)
- Interestingly, this AIHW report also notes under the heading “Effects of unmet need”: **Lack of access to appropriate disability support services** puts people with intellectual disability, ABI and psychiatric disability at risk of entering the corrective services system, people with disabilities in the prison population are not generally included in the estimates of unmet need for disability services (p 184)

Therefore according to the AIHW 2007 report, the projected growth of ABI (5.1%) should be of great concern to government and policy makers. It is discrimination against all people with ABI to let this historic neglect continue as it has.

*(The AIHW was commissioned by the Disability Policy and Research Working Group (DPRWG) to conduct this study to provide information on unmet demand for services provided under the Commonwealth State/territory Disability Agreement (CSTDA).*

**“Historically in Tasmania there has been a lack of specialist services for people with an ABI living in the community” The number of people surviving a brain injury and becoming disabled as a consequence is increasing and the problems of accommodation, support and care becoming greater. Many are ‘lost’ in the community, perhaps receiving services of some kind or other, but not necessarily identified as a brain injured person”** (*Tasmanian Acquired Brain Injury Service (TABIS) “Needs and Issues” – March 2002*)

## **The Historic Neglect of Tasmanians with ABI can no longer continue**

As the rate of ABI increases in Tasmania, supports for people acquiring a brain injury need to be funded adequately to provide equitable and appropriate services.

According to *AIHW Bulletin 55, December 2007: disability in Australia: acquired brain injury* Tasmanian’s with ABI has the second highest proportion of all service users 8%, with South Australia the highest at 10%. In contrast 4% of service users in New South Wales and Western Australia had ABI. These percentages account for individuals with ABI who are registered and are accessing services funded under the CSTDA. (These figures do not account for the many people with ABI who do not receive any services, or may never have been diagnosed as having an ABI).

Of the different service groups funded under the CSTDA, people with ABI were most likely to access community support, including services such as early intervention, therapy, case management, respite and accommodation support.

However, ABI specific community based services in Tasmania do not have the resources to respond to the current need of people with ABI, let alone the deal with the growing number of referrals received each year. (BIAT Issues paper 2006). If we are to seriously consider the statistics provided by ABS and AIHW as noted in this newsletter, how can this significant and growing issue be ignored and under funded any longer? It is time for action!

Resourcing of services and supports for Tasmanians with ABI should not have to be an uphill battle!

