



# Acquired Brain Injury Issues?.... Solutions?....

## **Final Community Consultation Issues Paper**

**April 2006**

*"Current support services for people with acquired brain injury (ABI) in Tasmania are fragmented and have allowed for the development of significant inequities across the State". An effective and equitable level of funding needs to be provided to address the current imbalance in service provision to meet the needs of people with acquired brain injury across Tasmania.*

*The Department of Health and Human Services "Review of Funded Services for People with Acquired Brain Injury" Final Report, August 1999*

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## BACKGROUND

In 1998 the Motor Accidents Insurance Board (MAIB) reduced the level of funding it provided to non-government organisations providing support for people with acquired brain injuries in Tasmania. The Minister for Health and Human Services at the time agreed to meet the subsequent funding shortfall “on the understanding that the services were reviewed and funding was allocated in the most effective and efficient manner”.

A Review was undertaken which included consultation with primary service providers, families, carers, clients and other service providers, with the final report – *Review of Funded Services for People with Acquired Brain Injury* released in August 1999. The Report contained a number of recommendations that were aimed at developing a state-wide service structure and achieving equity of service provision across the State.

Recommendation 15 of the Review stated: “There is currently \$626,000 available through the Department of Health and Human Services for supporting people with ABI in Tasmania. **This does not represent enough funding to meet the current level of need of this client group**”.

In September 2003, in response to requests for additional funding from ABI Service Providers across the State, Disability Services released a *Final Progress Report* on the recommendations of the Review of Acquired Brain Injury Services. The purpose of the *Final Progress Report* was to revisit the recommendations of the 1999 Review and report on whether or not they had been successfully implemented. The Brain Injury Association of Tasmania (BIAT) was invited to comment on Disability Services’ findings and BIAT’s response forms part of the *Final Progress Report*.

To date many of the issues identified in the 1999 *Review of Funded Services for People with Acquired Brain Injury* have not been addressed and the inequities that existed at the time of the release of the Review have further escalated. There has been very little increase in resources to the ABI Sector since 1999 and, as a consequence, the level of unmet need for people with ABI has increased considerably.

In October 2005, the Brain Injury Association of Tasmania (BIAT) conducted a series of community consultation sessions throughout Tasmania. The purpose of the consultations was to seek input from people with acquired brain injury (ABI), their families, carers and service providers on a range of issues, including the service system (or lack of) for people with ABI in Tasmania.

Invitations to attend the consultation sessions were supplemented with a consultation ‘*Discussion Document*’. This document briefly outlined previously identified issues, and invited participants to consider these issues further and to contribute their ideas and comments.

The primary issues in the ‘*Discussion Document*’ were:

- Supported Living Options (including shared homes, individual packages, transition models of support and respite);
- Rehabilitation;
- Employment options (for people with ABI);
- Support for people with ABI;
- Support for carers and family members; and
- Complex needs (including criminal justice issues).

The sessions were well attended in each of the three regions (Hobart, Burnie and Launceston), with representation from people with acquired brain injury, families and/or carers, and service providers.

In addition to a wealth of information regarding these specific issues, BIAT also received comments and ideas regarding a range of other topics such as employment issues for carers, community access (day support) options (including return to work placements, recreation and leisure programs, and unmet need), community awareness and education, research, transport, living in a rural and/or remote area, advocacy, case management/service co-ordination, dual diagnosis and specific issues for children with an ABI.

This information has provided BIAT with an opportunity to gain a clearer and more comprehensive understanding of the current service system issues (state-wide and region specific), and the experience of living with a brain injury in Tasmania from a range of perspectives (individual, siblings, parents, children, friends, extended family, service providers and the general community).

A Draft '*Community Consultation Issues Paper*', including a series of recommendations in response to the issues raised, was developed by BIAT from the initial '*Discussion Document*', issues and solutions provided at the Community Consultations and subsequent feedback; the recommendations also include those received throughout the consultation process.

In February 2006 BIAT distributed the Draft Issues Paper to a range of stakeholders. From this distribution BIAT received further feedback from people with brain injury, families and service providers regarding the content and presentation of information gathered throughout the consultation process. This feedback was incorporated into the Final '*Community Consultation Issues Paper*'.

BIAT is now developing an '*Action Plan*' which includes strategies for implementation of the Issues Paper recommendations. The BIAT '*Action Plan*' and Final '*Community Consultation Issues Paper*' will then be presented to Government. Reports against the BIAT '*Action Plan*' will be prepared on a regular basis to keep the community informed of progress and outcomes.

BIAT would like to take this opportunity to thank everyone who provided us with their comments, ideas and feedback.

## **The Acquired Brain Injury Population in Tasmania**

The most informative data about the ABI population can be drawn from those who report a degree of disablement from their brain injury. In 1998, approximately 5200\* Tasmanians stated that they experienced substantial disablement or interference with their activities as a result of their brain injuries (*Australian Institute of Health and Welfare 2003 – Disability Prevalence and Trends*.) The actual numbers of Tasmanians who have sustained an ABI is much higher, because many people with acquired brain injuries are undiagnosed.

*\* Excludes Stroke figures – The 1998 survey data separated Stroke figures from ABI figures because “although stroke is a common cause of brain injury, it does not always result in brain injury....”*

## **REHABILITATION**

While there is no cure for brain injury, the brain does have some capacity to repair itself and rehabilitation is crucial to recovery following a brain injury – it uses both the body's natural healing abilities and the brain's ability to relearn to aid recovery. As with all rehabilitation, the goal is to help the person achieve the maximum degree of return to their previous level of functioning. Rehabilitation also means learning new ways to compensate for abilities that have permanently changed due to brain injury.

In Tasmania, there are two formal levels of rehabilitation. The first occurs in the hospital/acute care setting. This form of rehabilitation is usually co-ordinated for hospital in-patients in wards which are rehabilitation specific or general medical. The level of access to this 'primary' rehabilitation varies, and is dependent on the resources within the facility, individual progress and can be complicated by the length of a person's stay.

Unlike other states in Australia, Tasmania does not currently have a 'transition' (or 'secondary') model of rehabilitation. In Tasmania, once a person is discharged from hospital, they will return to their home (or for some who may have been living independently prior to their injury, to the family home) and participate in community based rehabilitation. Community based rehabilitation may occur in a range of settings.

In general, the community based rehabilitation opportunities for people with brain injury differ significantly across our state. In the North and North West regions, community based rehabilitation is usually co-ordinated by the individual (and/or their family) and is available through community resources such as health centres and private practitioners. In the southern region, people can also access these services for rehabilitation, however there is an additional service available at the 'Community Rehabilitation Unit' (CRU). The CRU is an outpatient multidisciplinary model of rehabilitation for adults with 'complex' needs as a result of brain injury. There are also a number of Community Options (Day Service) and residential services that implement rehabilitation models of service delivery to people with brain injury.

### **Transition planning**

- There is a lack of transition support (including formal transition planning) from hospital to home for a person with ABI and their family/carer. Consultation participants reported a lack of relevant information being available to them at the time of their loved one returning to the family 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.

### **Access to rehabilitation**

- 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.
- Tasmanian residents who acquire a (non compensable) brain injury and require intensive rehabilitation must relocate or regularly travel to Hobart to gain access to this service. The Rehabilitation Ward/Unit in the Royal Hobart Hospital is insufficient to provide appropriate rehabilitation to all who require/deserve it. For families who live in other regional areas (including coastal townships, North and North West residents) this can have a significant financial, social and emotional consequence and has been identified as a contributing factor to

the breakdown of many families, school placements, social networks and employment arrangements for many people who are caring for a person with ABI.

- In the North West region of Tasmania, people with a brain injury, their families and carers highlighted they have not been able to access outpatient rehabilitation (stating this seems to only be available for people who have suffered a mild stroke). Consequently, families have advised BIAT that they are undertaking to provide the rehabilitation for their children and adult family members with ABI, without the guidance and/or support of therapists.
- Tasmania is experiencing a shortage of appropriately qualified therapists; this has been reported as particularly extreme in the North and North West regions of Tasmania (including East and West Coast areas and midlands).

### **Rehabilitation service gaps**

- There is a lack of commitment to cognitive rehabilitation with the 'visible' aspects of injury being the primary focus. In addition, there is a significant need to increase public awareness of both the impact and the cognitive outcomes of brain injury, particularly within the Education system.
- There is a need for rehabilitation to be provided to adults and children in an inviting, comfortable environment which includes opportunities for peer group support programs. This would enhance the participation and motivation of children and adults, particularly if activities of interest were introduced such as music, games, dance, quiz, sport.
- ABI needs to have a raised profile particularly in relation to the Statewide Rehabilitation Plan.
- There is a need for a clear pathway for people that provides opportunities for self determination, and a co-ordinated approach to achieve individualised goals.

### **Recommendations:**

- Development and distribution of a community services 'map' (including contact names, phone numbers, addresses etc.) to provide clear pathways for people with ABI and their families. This should be available in a range of formats and should be available in specific versions. (This recommendation also relates to *Community Awareness and Education*).
- Development, implementation and appropriate resourcing of quality community based rehabilitation models for children and adults with ABI in Tasmania.
- Research to be conducted regarding the rehabilitation opportunities in Tasmania in comparison to national trends; and research which demonstrates the differences in outcomes for people who are able to access rehabilitation, in particular the differences between people who receive financial compensation versus those who are non-compensable.
- Greater government awareness of the need for increased rehabilitation services for Tasmanian's who live in North and North Western regions, including out-patient services.
- Where appropriate, families and carers be provided with appropriate support and education to provide rehabilitation.
- The development of a national definition of rehabilitation which has a functional application; this definition to also acknowledge life roles.

- Individual transition planning to begin at the time of diagnosis (consistent with best practice in other States and jurisdictions). This planning should include documented pathways for service access, timeframes and should identify responsibility for implementation of actions.

## COMMUNITY AWARENESS AND EDUCATION

Given the wide impact of brain injury, people with an ABI, their families and carers, service providers (especially those intending to provide services to people with ABI) and the general public all need consistent information about the causes, consequences and prevention of ABI; they also need to continuously supplement and extend their knowledge.

Whilst some generic services are providing quality services to support for people with ABI, there are a number of services (for a range of reasons) that attempt to do so within a philosophical framework and operational culture designed for people with an intellectual disability. In the absence of specialised training, many of these services are inappropriate and in the longer term are often detrimental for people with cognitive and executive functioning deficits.

### Timely access to accurate information

- There is a need for an increase in the availability, accessibility and awareness of information regarding brain injury. In particular, this information is required in a range of formats for people (children, adolescents and adults) who have a brain injury, for children whose parent/s or siblings have a brain injury and for people who have assumed a caring role of a person with acquired brain injury. One topic highlighted as being of specific importance is the issue of 'grief' following an acquired brain injury, particularly regarding support to children and their families.
- It is vital that this information is available to the community at a range of outlets (hospital, medical centres, GP surgeries etc), and is accessible at various times during recovery/rehabilitation (hospital, therapy, community rehabilitation, home etc).

### Education regarding brain injury

- 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. Industries which have been highlighted as *a critical priority* for education are Regional Hospital staff (particularly Emergency staff, Paediatric and Allied Health staff), General Practitioners, disability services (including government and non-government services), Education services (particularly classroom teachers and classroom aides), Child Care providers, Housing services (including government, non-government and private), Police, Welfare services, Advocacy services, Criminal Justice services, Aged Care services, transport services (including taxis and bus companies), carers, support workers and employees within the retail and hospitality industries.
- Educational programs and materials aimed at service provider audiences should include key principles for interactions with people with ABI such as privacy (particularly for couples in hospital settings), objectivity, respect (including communicating and interacting directly with the person with ABI – not 'through' a support person), active listening and patience. This education should also focus on educating the community about the philosophies of service delivery which are appropriate for people with ABI and which promote choice, self-determination and autonomy for people with ABI.



- People with ABI in Tasmania have voiced their concerns about informing others that they have a brain injury. They have indicated their appreciation of the fact that this may constitute a barrier for community understanding and awareness of ABI, but acknowledge they are likely to be treated 'differently' (less respected and/or devalued) when they advise others of their situation.
- Consultation participants expressed an interest in BIAT's role being more clearly and broadly communicated to achieve a greater profile within the community.
- Appropriate resourcing for BIAT to assume a hospital/acute care liaison role. There is a significant need for regular visits to each of the regional hospitals to provide information, support and regular referral support to staff, individuals and their families.
- There is a need for a 'whole of government' approach to and acceptance of responsibility for brain injury prevention and awareness programs such as BIAT's 'Custody for Life' program.

### **Recommendations:**

- Development and implementation of an effective ABI information system which is able to respond in a timely manner to a range of audiences, interests and needs. This to include the following:
  - Development and appropriate distribution of regularly updated *Brain Injury Information/Fact Sheets* which are available in a range of formats and on a range of topics. This will ensure there is consistent, high quality literature/information available both prior to and post discharge. In addition, this information to be tailored to address individual situations and need.
  - Development and distribution of a community services 'map' (including contact names, phone numbers, addresses etc.) to provide clear pathways for people with ABI and their families. This should be available in a range of formats and should be specific to the regional area where the person with ABI lives. (This recommendation also relates to *Rehabilitation*).
  - Resourcing of an appropriately trained hospital/acute care liaison role. This role would provide regular visits to hospitals in each region to provide staff, individuals and families with appropriate information, support and referral.
- Research to be conducted which gathers information from the perspectives of children regarding their experiences of living with a person with ABI. This information would then be used to develop a resource which responds to the specific needs of children who have a sibling, parent or extended family member with ABI. This should be done in partnership with other agencies/organisations such as the Education Department, Carers Association, TASCARE Society for Children and the Association for Children with Disability (Tas).
- Increased opportunities, including training, be created and resourced for people with ABI, their families and carers to participate in the presentation of community education programs.
- BIAT training modules be modified to include more comprehensive materials and content:
  - 'From the family perspective' – particularly the impacts on the family when a family member acquires a brain injury.

- Regarding dual diagnosis; the perspective of many in the disability community/sector is that dual diagnosis comprises intellectual disability/mental illness only. The wider community needs to be aware that issues such as alcohol/drug abuse, mental illness, and a higher risk of suicide are common outcomes following an acquired brain injury.
- Relevant to the provision of support from and within Aged Care Services.
- A 'whole of government' commitment to the allocation of sufficient resources to enable an increase in the number of brain injury prevention programs across the State presented to children and young adults (including BIAT's 'Custody for Life' presentations for Police/Youth Justice).
- Allocation of sufficient resources in the community to allow for an intensive education campaign to the service providers and community groups who were identified as 'critical priority' during the community consultation process.
- Development of 'awareness' initiatives and media campaigns which focus on principles of community acceptance for people with ABI, including a national media campaign/s incorporating high profile personalities to raise awareness of brain injury. This could include a campaign for people with ABI to 'speak out'.
- 'Awareness of ABI' to be included in educational/training curriculum for disability, medical, retail, and hospitality industry staff, and in induction training for childcare, education, and correctional health staff, and police cadets.
- Articles on ABI to be regularly included in relevant publications which will provide educational opportunities for the community, for example, the regional Division of General Practitioners and/or Disability Services newsletters.

## RESPIRE

Long-term carers find that 'surviving' is a matter of taking time out for themselves. Part of this may just be taking time for a cuppa during each day but often longer breaks are needed. Respite care is an essential part of the overall support that families may need.<sup>1</sup>

- There is a lack of appropriate respite available for children and adults with ABI. Currently in Tasmania, there are limited options available to people with ABI and their families for in home or residential respite options. Those respite services which are available are primarily designed to support people with intellectual disabilities and/or aged persons (in residential aged care facilities). These service models and settings are not appropriate supports for a person with ABI.
- Tasmanians affected by ABI have revealed a significant and pressing need for respite models which are affordable, age appropriate and are staffed with support workers that are educated regarding the needs and best practice service delivery models for people with ABI. These respite services should be available in a community based and/or home based setting and should focus on offering flexible, needs based services which are part of a planned, individualised support program.

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<sup>1</sup> Brain Injury Association of Queensland Fact Sheet : Respite Care

- There is a lack of appropriate respite available for children and siblings of people with ABI. Opportunities for children to attend peer group activities and respite camps are critical in helping children develop coping strategies, knowledge and understanding and to develop and maintain friendships.
- Respite services for people with ABI should recognise and respond to the needs of the person with ABI *and* the needs of their families and primary carers. Services should consider limiting the pressures on carers and families by minimizing 'paperwork' prior to each respite visit/session.
- Tasmanians with ABI and their families/carers have highlighted the need for a service directory specifically listing organisations that provide support to people with a disability on interstate and overseas holiday options.

### **Recommendations:**

- Disability Services amend the guidelines for individual support regarding respite to include families and carers of a person with ABI as the nominated 'client'. This would result in more comprehensive, flexible support being available to families.
- Development and implementation of appropriate and meaningful respite facilities and service options in Tasmania for people with brain injury and their families/carers.
- Research to be conducted which provides evidence regarding the 'need' for additional models of respite for people with ABI in Tasmania. This research can then be used to educate Government and community on appropriate models of respite.
- Brain injury (causes and impacts) to be more clearly understood by the community so there is appropriate recognition of the importance and need for access to respite as a critical pro-active support in the prevention of relationship and family breakdown. This includes access to respite service provision for children, siblings, partners and/or parents of a person with ABI.
- BIAT acknowledge there needs to be a balance of appropriate levels of documentation and maintenance of quality, high standards of care and support. However, services which provide respite to people with ABI, their families and carers need to limit the 'paperwork' demands on families and carers.

## **SUPPORT FOR PEOPLE WITH ABI**

A brain injury is potentially one of the most devastating disabilities, with a huge range of effects due to the complexity of the brain. The number and severity of problems resulting from a brain injury will differ from person to person because each individual's brain injury varies in the extent and location of damage. The extent of some of these changes may only become apparent as time progresses.

- People with ABI in Tasmania have indicated they often feel frustrated, vulnerable, anxious and alone. Social isolation is one of the greatest contributing factors for experiencing these feelings.

- People with ABI and their families/carers have highlighted a significant need for access to relationship counseling, particularly relating to communication within a relationship. Feedback has also highlighted the need for the community services to be aware of the differences between ABI, and Mental Health support needs. Again, this highlights the need for increased levels of community awareness and education to ensure that service providers are knowledgeable and well equipped to respond to the needs of people with ABI and their relationships.
- People with ABI need the opportunity to debrief with someone outside of the traditional 'day support' hours (9.00am to 3.00pm). Ideally this service would link them into a service consultation the following day, if required. People with ABI "don't always want to talk with family/friend" as they don't want to "worry, burden or upset them". Also, sometimes the problem involves their carers/family.

### **Recommendations:**

- Development of partnerships with community based counseling services (including telephone counseling services), to include the provision of general training and education to staff, and individualised services to support counselors to respond to the individual needs of their clients. This is particularly vital for relationship counseling.
- Implementation of a promotional campaign regarding counseling services in Tasmania, including cost, access, locations, etc.
- Regular professional counseling be available for people with brain injury, especially in the early stages following their injury/diagnosis.

## **RURAL AND REMOTE, including ACCESS AND TRANSPORT**

Rural disadvantage denies access to services for a large number of Tasmanians with ABI. For adults and children with ABI who live in rural areas, their problems are further compounded by a greater paucity of community services and the geographical dispersion of available services across vast areas.

### **Living in a rural and/or remote area of Tasmania**

- There are extremely limited services which offer support to people with ABI, their families and carers who live in rural and remote areas of Tasmania. These people have indicated as a result, it is common that they will become dependent on their local General Practitioners for information regarding information relating to their ABI.

### **Access to services**

- As a result of limited services available, particularly in the North and North West regions and coastal areas of Tasmania, many people who acquire a brain injury are required to travel to Hobart (and sometimes Launceston) to receive medical and therapeutic services. At these times, family members, carers and/or partners may also relocate in order to provide ongoing support to their loved one. This means that family members and people with ABI require suitable accommodation services in an unfamiliar region for varying (and sometimes unpredictable) lengths of time (a few days, or for several months). Families and carers have informed BIAT they manage this situation by staying in hotels (expensive, and an added pressure) or they will make informal arrangements with extended family and/or friends (impacts on privacy, etc). There is a significant and urgent need for short term, affordable, local

accommodation to be available for family members from rural and remote areas when patients are in hospital (including Launceston, Burnie).

### **Transport within and between communities**

- Transport options in Tasmania are limited. For those people with ABI who live in urban centres (Launceston, Burnie, Hobart) there are some wheelchair accessible taxis, but this is an expensive service, often limited by availability. For others, there are few or no accessible transport services in their local community. This results in an inability (or at least, a reduction) in the person's capacity to participate in therapeutic services, and ultimately contributes to social isolation.
- Residents of King Island reported experiencing financial difficulty as a result of the expense of air travel between their home, and the regional centre of Burnie, to access their necessary rehabilitation and support.
- People with ABI have expressed feeling vulnerable when accessing public transport. Specifically these comments related to taxi drivers' knowledge of safety processes when securing wheelchairs into vehicles, and being in situations where the taxi driver undertakes the 'longest distance' to the persons required destination.
- In addition, people with ABI have reported experiencing difficulties in reading and interpreting public bus timetables due to the small font size of print and amount of information contained on one page.
- Given the social isolation experienced by many people with brain injury, there is a significant and urgent need for motor vehicle driver services for people with ABI statewide but particularly in North and North West regions of Tasmania. This includes driving assessments and educating General Practitioners on the need to re-assess 'capacity' to drive for people who have limitations such as problem solving, reasoning, organisation, memory, vision and insight as a result of their brain injury.

### **Access to venues**

- General access to public venues and buildings is still reported as problematic for people with physical disabilities. In particular, issues were raised regarding cluttered doorways, footpaths and cars which partially park over footpaths.
- Whilst the Tasmanian *Building Standards and Regulations* include provisions for accessibility for commercial properties, no such regulations are available for residential buildings. Similarly, there are difficulties with creating greater accessibility to heritage listed properties.
- People with ABI, their families, carers and service providers noted significant inconsistencies in the allocated timeframes and quantity of disabled parking zones for peak access areas across Southern and Northern Tasmania.

### **Recommendations:**

- Review of the Patient Transport Scheme, in particular in relation to a reduction in fare costs when travel is supported by a General Practitioner as necessary for medical/rehabilitation purposes, for example, travel between Burnie and King Island.
- Information and education to be provided to General Practitioners (regarding driving assessments), private transport companies (including taxi services) and local councils

(accessibility of footpaths, parking) in Tasmania to raise awareness of ABI and improve the experiences of people with ABI in Tasmania.

- Bus companies to ensure documentation regarding services such as timetables and tickets (cost, purchase option) is available in plain English versions and in a range of print formats (including electronic information) relevant to people with ABI.
- Affordable accommodation options to be available for families who are required to re-locate while their family member is receiving treatment (hospital or intensive rehabilitation).

## **COMMUNITY ACCESS (DAY OPTION) SERVICES**

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 Acquired Brain Injury. ABI clients have an ongoing disability and their needs are best addressed at an early stage of rehabilitation to achieve positive outcomes.....Only a small percentage of current clients of ABI specialist services are compensable (approximately 8%) meaning that funding needs to be provided from other sources to supply support services. Currently ABI specialist services in the state receive a limited level of funding. The services do receive some IOP funds as well to meet some specific needs but this does not address all core service provision needs."

### **Role of Community Access (Day Option) services**

- Consultations with people with ABI and key stakeholders in their lives have indicated a strong interest in Community Access (Day Option) services offering opportunities for access to *centre* and *community* based programs. They have defined the focus of these services as needing to provide goal oriented, individualised services which are consultative, age appropriate, regularly reviewed and are provided in safe, comfortable environments. At these services, people with ABI have indicated they want opportunities to develop skills which enhance their independence, insight and participation in life (including establishing and maintaining relationships and linkages with career planning and options).
- It is also essential that Community Access (Day Option) services for people with ABI provide support which is consistent with the person's rehabilitation program. This will ensure the person has the greatest opportunity to achieve their defined rehabilitation goals.
- Community consultation in Tasmania has highlighted an interest and need for people with ABI to access programs which offer them enhanced opportunities to re-gain their independence - for example, practical, "take home" skills such as cooking, home duties, access to public transport.

### **Access to Community Access (Day Option) services**

- Community Access (Day Option) services for individuals with ABI continues to be highlighted as a 'gap' within the Tasmanian service system. There is significant need to increase the capacity of service providers to respond to the needs of the Tasmanians who have a brain injury. Although a significant issue statewide, this is particularly critical in North West region where there are no formal programs available, contributing further to the issues of social isolation for people with ABI and their families. This is also an issue for people with ABI living in aged care residential facilities.
- People with ABI, their families, carers and service providers have indicated that there is a need for meaningful Community Access (Day Option) services in rural settings. At present,

Community Access services are extremely limited in the provision of traditional day option programs in rural settings due to venue accessibility issues and cost.

### **Hours of operation**

- The hours of operation for centre based Community Access (Day Option) services should reflect the work arrangements for the general community. For example, centre based programs should be extended to operate between 9am and 5pm, every week day. There is a greater need for this to occur in the North and North West regions.
- However, the Tasmanian community also believe that the hours of service provision for home and community based day option services need to be more flexible (i.e. outside 9am – 5pm) and be determined based on individual need.

### **Recreation and leisure programs**

- In addition to programs which focus on skill development and maintenance, there is a significant need to increase social and recreational programs available to people with ABI in Tasmania (including evenings and weekends). These programs would include opportunities to participate (with support) in activities which reflect people's interests, hobbies and which support people to re-kindle and/or develop and maintain new and genuine friendships and family ties.

### **Employment related Community Access (Day Option) programs**

- People with brain injury have indicated the need for an increase in support to access formal education and training as a means of creating employment opportunities for their future.
- In addition, there was also strong interest in considering the role of Community Access (Day Option) service providers linking in with Return to Work programs and Work experience placements to support skill development, motivation and self esteem.

### **Recommendations:**

- Appropriate, adequately resourced Community Access (Day Options) services should be available throughout Tasmania to people with ABI, and should offer individuals choice regarding:
  - Service operation hours which reflect the work arrangements for the general community;
  - Consistency as a core principle of individualised person centered support across a range of services;
  - Flexible outreach and referral services.
- Establishment of appropriate Community Access (Day Option) options in the North West to provide people with ABI with centre and community based program opportunities as described earlier in this report. It is anticipated this will address social isolation issues for people with ABI in the North Western region of Tasmania, who also are at risk of involvement with the criminal justice system and mental health services.
- Resources for the establishment of a "Slow to Recover Support Program" initiative in Tasmania to respond to the needs of people with moderate to severe physical/ cognitive support needs. This will enable services to specialise in "active rehabilitation", reduce the extensive wait list for

services and result in a greater flow through for people with mild to moderate cognitive/physical support needs.

- Community Access (Day Option) services should be comprehensive and global in their approach to identifying individual need. Where a person's need is outside the scope of the training, skills and role of the Community Access staff/service provider, the Community Access service should co-ordinate referrals to appropriate agencies (such as grief and/or relationship counseling).
- Active and passive service streams are required in order to meet individual program needs and interests.
- Funding available to specific ABI Community Access (Day Option) services should be equitable to Community Access (Day Option) service providers for other disabilities.

## **HOUSING AND SUPPORTED ACCOMMODATION**

### **Service gaps**

- Supported accommodation options within Tasmania for people with ABI are extremely limited. Whilst there are some shared home (group home) placements available, this model does not effectively address the needs of people who wish to remain living in their family homes, live with their partners, live independently and/or who require transitional and/or crisis accommodation.
- Inappropriate accommodation placements and limited supports in the community commonly result in a loss of contact with services, itinerancy and homelessness.
- In general, people with brain injury are experiencing lengthy delays in their transfer from acute care in a hospital setting to their community home (own home, shared home, placement etc). The reason for these delays is usually related to allocation of appropriate resources (individual funding or home modifications). Particularly for people with high physical and/or cognitive support needs, this experience is likely to further compound their level of disability and opportunities for rehabilitation.
- Inappropriate involvement with the justice system and acute psychiatric services can be partially attributed to poor accommodation support. Tasmania requires a significant increase in the availability of accessible housing, individually funded packages, and supported home environments for people with acquired brain injury.
- Supported accommodation needs to be viewed as part of the rehabilitation continuum.
- People with ABI should be able to make informed choice regarding the people they will live with and where they live (which needs to be accessible to the community).
- At present, the Individual Support Package (ISP) funding initiative is proving to be quite restrictive for some individuals. This initiative is aimed at providing greater self choice and determination for people with ABI in the delivery of home and community based services. However, people with ABI have reported their ISP support as 'restrictive' and 'inflexible'. Primarily this is because support times are often dictated by the availability and flexibility of specific staff members of a selected organisation. Individual allocation of support must remain flexible in order to address the unique aspects and needs of each person with ABI.



- In February 2006, The Tasmanian and Commonwealth governments committed to a strategy which ensures that all young people with ABI who are currently supported in residential aged care facilities (often in high care – secure units) be moved out of those arrangements and into models of support which are age appropriate, recognise and respond appropriately to each person’s ABI related support needs. The state government needs to inform the community the details of the proportion of funding which will be available to support this in Tasmania and how this funding will be used.
- In Tasmania there is an inequity of access to appropriate accommodation supports for people with ABI. Essentially, this results in people who receive financial compensation for their ABI having a greater range of choice and options for accommodation supports.
- There is a significant need for Tasmania to develop and implement a pro-active approach to the issue of accommodation for people with acquired disabilities.

### **Access to appropriate housing**

- There is a severe shortage of affordable, accessible housing stock with long term lease arrangements within Tasmania, in both the private and public rental markets, on a statewide basis.
- There needs to be recognition of the need for rental options which also respond to cognitive support needs of some people with ABI. For example, touch sensitive hot plates, temperature controlled water faucets.

### **Shared supported accommodation (‘group’ home)**

- Existing models of supported accommodation (‘group’ homes) are not suitable for *all* people with ABI. Future models of supported accommodation should consider alternatives to the traditional ‘group home’ model (four people living in one house with staff support) which would be appropriate and meaningful to people with ABI who are parents, are married etc. These models may include ‘clusters’ of individual units with residents sharing outreach support.

### **Family homes – change in value**

- Some people are able to return to their own/family home following their ABI, but may need their homes modified to ensure the persons safety and accessibility to the property. This can be a lengthy process, which often means the person with ABI will continue to be cared for in a hospital system, despite no longer requiring medical attention. Whilst some homes may require minor alterations (installation of hand rails), others may require major renovation (new bathroom, ramp entries), or be required to sell their home to purchase a more suitable and accessible property. All of these options have financial implications.
- Feedback received from people with ABI and their families is that they often feel their homes are often ‘less’ attractive as a result of modifications.

### **Transition models of supported accommodation**

- In Tasmania there are few services, with very limited resources available to assist people with acquired brain injury to adapt to life after hospital. This is problematic, as it is usually not until months or even years after an injury that the true functional impacts of any deficits are realised. After leaving hospital, individuals often experience difficulties in a number of areas including independent living, relationships and returning to work. Many will develop secondary psychological disorders such as depression, anxiety, anger management problems, and

substance dependency. If these types of difficulties are not effectively managed they can escalate to increasing levels of distress for individuals and their families.

- Tasmanians with ABI and the key stakeholders in their lives have highlighted a critical need for Transition models of supported accommodation. This model of supported accommodation would offer opportunities for people with ABI and their families/carers to begin to adjust to the changes in their lives, re-integrate to the community and re-learn the skills of daily living in a safe and supported environment. This would decrease the likelihood that people with ABI, their families and carers would experience breakdown in their relationships, accommodation, and other risk factors associated with homelessness.
- A Tasmanian model of Transition Living would facilitate a smooth transition from hospital based care to living as independently as possible in the community. This would require a collaborative approach with existing programs and service providers within the Tasmanian community to ensure access is available for timely and appropriate assessments, rehabilitation, therapy, information and independent living skills training. It is essential that Tasmanians are able to access this model of support in all regional areas.

### **Recommendations:**

- A significant increase in the availability of accessible housing, individually funded packages, and supported home environments for people with acquired brain injury.
- Raised community awareness of the critical need for resources and a commitment by the Tasmanian Government to resource and establish appropriate transition models of accommodation for people with ABI.
- People with brain injury to have access to flexible support options which allow for actual self determination, choice and are reviewed by the individual with their key supporters. This is particularly critical for individuals with ABI who are inappropriately placed, or at risk of being inappropriately placed, in residential aged care settings.
- Housing service providers (including government and private rental arrangements) to receive information and education regarding the accommodation needs of people with ABI, including consideration of balance and memory issues.
- Collection of national and international data to provide evidence of the (mounting) cost benefit to Government for early intervention, intensive support and transition models of accommodation for people with ABI versus the cost of being supported in acute care bed in a hospital (for up to 3 years).
- Investigate the opportunity for people with ABI and their families/carers to utilise community health/multipurpose centres as campus of support in rural and/or remote areas.
- Investigate options for people with ABI to be able to purchase their own homes. This includes highlighting the need for recognition from financial institutions to acknowledge compensation as 'ongoing' income which can be used to secure home/personal loans etc.
- A significant increase in the quality and level of participation for person with brain injury and their key stakeholders in discharge planning from acute care settings.
- Appropriate models of accommodation support for people with ABI, their families and carers (including cluster unit models, independent living support options, shared home options,

transitional and crisis arrangements) which are adequately resourced and appropriately implemented.

## **RESEARCH**

Whilst there are hundreds of service users with ABI in Tasmania, the actual level of need of people with ABI in Tasmania remains largely unknown. Very little ABI research exists in Tasmania that places an emphasis on the service system and models of support. Recent government initiatives and pilot projects aimed at researching and developing improved models of response for people with a disability have ignored the needs of people with ABI. Collaboration, alliances and taking an open minded, cross disciplinary approach to research will open up opportunities for greater success in ABI research.

- There is a significant need for evidence regarding the incidence, extent and the impact of ABI in Tasmania. This research will assist BIAT and the Tasmanian community to be able to clearly identify and respond to the need of individuals, their families/carers and general community. It will also assist in the development and implementation of prevention campaigns.

### **Recommendations:**

- Development and implementation of data collection system which is able to identify and support statistical analysis of the incidence, type, causes and outcomes from brain injury in Tasmania.
- Review literature and/or facilitate research on the incidence and impact of brain injury on individuals, their families and carers.
- Develop partnerships with organisations in Tasmania (including research units at local universities, social research organisations) who may be able to focus areas of research and resource development on ABI.

## **SUPPORT FOR PRIMARY CARERS**

The diverse effects of a brain injury create multiple impacts on relationships and families. Families and carers commonly experience psychological, medical, social, emotional and financial difficulties associated with the caring role.

- Representatives of carers and families (including siblings) have indicated they require increased levels of support as they respond to the changes in their lives, and the life of their loved one with ABI in the early stages in hospital and later, the community. In particular, they have reported that the supports which are evident in the early stages following a person's ABI are likely to withdraw relatively quickly, leaving carers to manage their situation on their own.
- Carers and families have highlighted their experiences of isolation, fear, financial hardship, extreme exhaustion and need for access to information and support. These experiences appear to be more marked for people who live in rural and/or remote areas of Tasmania.
- For some people the intensity of their role of caring for their loved one with ABI means they are not able to continue/return/undertake positions of employment. These situations are isolating, financially strenuous and challenging. Similarly, the situations for carers who maintain their

positions of paid and/or voluntary employment external to their caring role have a great need for recognition, particularly of the unique needs of this group.

- There is a clear need for mobile outreach information and support to assist families and carers – including advice and mentoring regarding appropriate ways for families and carers to respond to challenging behaviour (including modeling),
- Other issues of relevance and concern reported by families and carers of a person with ABI included loss of friendships, contact with immediate and extended family members and poor self image.
- There is a need for greater recognition and service response to people who require parenting skills support following an ABI. In particular, this relates to the parental rights/roles and responsibilities for raising and educating children, determining a need for access to counseling for children, (adjustment / emotional impact), and support to deal with separation from children whilst in rehabilitation.
- There is a significant need for carers and families to feel valued, including being publicly recognised for their commitment and support to their family member with an ABI.
- Families of people with ABI, particularly in the North of Tasmania indicated an interest in starting up 'mentor/support' group to provide moral support to others in a similar situation.

### **Recommendations:**

- Implementation of a direct contact support service for people with acquired brain injury and their families in the hospital setting, as required. This service would provide a continuum of support to people and their families from acute care to community, and provide information regarding services and supports which are available in the community.
- Conduct research regarding parenting support programs within Tasmania that will address the issues raised in the community consultations. Distribution of research findings and outcomes to appropriate services (for example children, education and health services).
- Establishment of family support groups in cities and regional areas, including opportunities for guest speakers and topics of interest as well as social 'get togethers' to address isolation issues.

## **BEHAVIOUR**

Cognitive and behavioural needs tend to escalate after an acquired brain injury. Rather than deal with cognitive and behavioural issues, services in Tasmania are generally designed to address medical, nursing and therapeutic needs. At times, some people with ABI may present with challenging behaviours, posing risks to themselves, the community, and those who support them. As a result some individuals are excluded from receiving services while others experience criminal justice involvement. For many people with ABI, challenging behaviours can be appropriately managed with involvement from health professional's support and intervention, and community education.

- There is an identified lack of specialist behaviour management services and support available across Tasmania. This is particularly evident in North and North West regions and in the public health system statewide. There is a need to investigate and implement strategies that will

provide access for families and service providers in rural communities to behavioural intervention services.

- There are long waiting lists for professionals, particularly Disability Services' Resource Team; and when services are received people have provided feedback that the intervention is often inappropriate as it was developed based upon the intellectual disability model.
- Due to the lack of knowledge, understanding, experience, skills and resources in regard to supporting a person with ABI who exhibits challenging behaviour, the responses from family members, carers and professionals are commonly misguided and poorly implemented.
- The marginalisation of people with acquired brain injury adds to the high incidence of isolation, frustration, depression, risk taking behaviours, and drug and alcohol abuse. This increases the incidents of challenging behaviour and adds to the complexities of service provision.
- Behaviour support needs to occur in environments where the person is comfortable.
- Active behaviour management programs need to be promoted as part of individual program supports.

### **Recommendations:**

- People with ABI in Tasmania, their families and carers (including those who live in rural and remote areas) to have access to quality, specialised behaviour intervention support which responds to their situation and needs in a timely, appropriate manner.
- Adults and children with ABI to have access to public therapy services in a timely manner – particularly those whose brain injury is not associated with a compensation payment.

## **FINANCIAL SUPPORT**

### **Compensability**

The division of people with ABI in Tasmania into 'compensable' or 'non-compensable' categories compromises equity in service provision/funding. A "two tier" service system exists as some people who sustain brain injuries are compensable under insurance schemes, whilst others are reliant on their own personal incomes/savings or those of their primary carers because their injury was not compensable.

- In Tasmania, there are significant differences in service access for people with and without financial compensation for their ABI. This includes rehabilitation, accommodation, counseling, financial support (personal income, home modifications, specialist purchases) and information.
- People who do not have, or are awaiting payment of financial compensation have reported experiencing difficulties accessing State Disability Services for support and information.

### **Health Insurance**

- People with ABI and their families and carers have expressed dissatisfaction with the medical rebates available through private health funds relating to ABI related expenses.

### **Carers payments**

- People who are in receipt of the *Commonwealth Carers* pension have reported experiencing difficulties accessing domestic help.

## **Recommendations:**

- State Government Disability Services to provide access to support, in a timely manner, for people whose brain injury is non-compensable, so as to maximise their capacity and opportunities for rehabilitation.
- State Government Disability Services to undertake education/training regarding brain injury, including impacts and outcomes. This will ensure that responses to request for support from people with ABI and their families are appropriately managed.
- Research to be conducted regarding the implementation of a 'no fault' insurance scheme in Tasmania. The findings of this research should be available for public access.

## **CASE MANAGEMENT/SERVICE CO-ORDINATION**

### **Current services**

- In Tasmania, people with ABI who have not received compensation are able to access a model of Service Co-ordination from the State Government Department of Health and Human Services (free service). In particular, this service aims to provide information and service linkage supports to people in an attempt to enhance their independence and participation in the community. However, participants of the community consultations have clearly indicated their dissatisfaction with the 'Service Co-ordination' model and service. Comments reflected the current model as 'ineffective', 'inefficient' and 'not specific to addressing the needs of people with brain injury'. Feedback suggests that the level of complexity, which is required in the co-ordination of care, support and services in the early stages of diagnosis and rehabilitation, would be better addressed by a Case Management model of support. Whilst there are examples of some positive outcomes, in general, community feedback has suggested that people in the role of Service Co-ordination are not familiar with the needs of people with ABI, or the appropriate services in the community to facilitate referrals and/or contact.
- The ABI Sector fully supports the need for 'needs based assessment.' Unfortunately anecdotal evidence received by BIAT suggests that needs based assessment which is sensitive to the cognitive needs of people with ABI is not utilised by Disability Services and, as a consequence, people with ABI are missing out on much needed services for which they would otherwise be eligible.

### **Disparity between private and public services**

- Again, Tasmanians have reported experiencing a significant disparity between the opportunities for people with ABI who are in receipt of financial compensation versus people who are reliant on private income or a pension for their daily needs. The community consultations have revealed the majority of people who access public services (those in receipt of a Disability Support Pension or private income) are dissatisfied with the quality (poor service which is time consuming and not responding to their needs) and quantity of resources (too few staff with too few skills) which are available to maximise their rehabilitation and development post injury.

### **Case management for the future – an appropriate model**

- There was 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 co-ordination of referrals, planning, rehabilitation, information and support continuum to these families.

- This service should offer a consultative, considered approach to life and skill planning (including rehabilitation) which is focused on individual need, establishment, monitor and review of personal goals and outcomes and service linkages within the community. In addition, the Tasmanian ABI community requires a Case Management service which will ensure the provision of timely and accurate information and meaningful support as a continuum between acute care and community re-integration (including discharge planning and referrals to community services).
- People with ABI and their families require services which are meaningful, accountable and which are able to respond to the needs of the individual and their carers.

### **Recommendations:**

- The Tasmanian Government to provide an effective and efficient service co-ordination/ case management model which is able to recognise and respond to the needs of people with ABI. As previously mentioned in the Community Education and Awareness section of this report, it is essential that staff within the Service Co-ordination/Case Management branch have a sound understanding of brain injury, it's impact on individuals, their families and communities. This education will ensure that people with brain injury's needs are identified and responded to in a timely and appropriate manner.
- Consistent with recommendations of the Department of Health and Human Services "Review of Funded Services for People with Acquired Brain Injury", Final Report, August 1999, legislative changes are required to incorporate 'cognitive impairment' within the Tasmanian Disability Services Act.

## **EDUCATION and EMPLOYMENT**

All people with ABI in Tasmania are eligible to access Commonwealth funded employment services (generic and disability specific) and business services. There are also specialist disability Commonwealth funded employment services. However, employment rates for people with ABI (approximately 2%) are significantly lower when compared with other disability groups (i.e. intellectual disability approximately 40%).

### **Initiating and/or returning to Study**

- Tasmanians with ABI have reported a number of difficulties associated with initiating formal education/study post their ABI. TAFE Tasmania is one learning organisation which was highlighted as having the potential to be restrictive for people with ABI as students are required to identify a clear learning pathway prior to commencement of study. This may be restrictive for people with ABI who are requiring access to courses to learn or re-learn specific skills (i.e. computer use) rather than needing/wanting to complete an entire qualification. Opportunities to participate in re-learning and skill development are critical in the rehabilitation process for people with ABI.
- There is a need for training/education organisations to provide flexible learning options (including on-line and/or self paced learning) to support people with ABI who may be affected by fatigue, motivation or who may need to budget for their learning.

- Education facilities need to offer appropriate equipment to allow access to learning for people with ABI.

## **Employment**

- The Tasmanian community should be encouraged to value the contributions made by people with acquired brain injury who undertake part time and/or voluntary positions of employment.
- People with ABI have highlighted they require employment opportunities which are 'meaningful' and support them to have valued, respected roles in the workplace, and the community in general.
- People with ABI have reported experiences that reflect a lack of understanding regarding ABI on the behalf of employers. There is a need to educate organisations to consider the support needs for people with ABI on an individual basis, as with other employee's. *(Please note a recommendation reflecting this issue has been included in the Community Awareness and Education section of the Issues Paper).*
- Many people with ABI are not aware of the options for employment and/or skill development which are available to them – including the services to assist them to achieve their employment related goals.
- Similarly, there is a need to ensure that support provided by employment support staff is respectfully matched to the support needs of the person with ABI. If this is not appropriately managed, people with ABI in the workplace will continue to feel isolated, undervalued and not 'included'.
- People with ABI and their families and carers, have identified they feel that agencies which offer employment support/placement Co-ordinators have a greater interest and focus in placement and support for people with an Intellectual Disability, than for people with ABI.

## **Barriers to participation in study and employment**

- Transport to/from the location of study or employment can be a barrier for participation, particularly for people who require transport skill training or live/work/study in outer suburbs.
- There is a need for the broad range of advantages and incentives (self confidence, socialisation, skill development and relationships) for participating in the workforce to be promoted to people with ABI. This is particularly relevant for people with ABI who receive a regular living allowance as part of a compensation arrangement. Some of these people indicated they did not feel motivated to participate in the workforce as they did not require the financial income.
- Whilst some Tasmanian services provide targeted vocational rehabilitation options, many services do not provide intensive support (one-to-one) for people with brain injury within a workplace.
- Generic employment support services often avoid people with ABI due to the complex nature of cognitive impairment and the need for extended support.



## **Recommendations:**

- Accessible information and support to be available, in a range of formats, to people with ABI regarding:
  - the benefits and advantages of employment (other than financial rewards) – such as increased confidence, social opportunities, skill development, etc.
  - employment and/or skill development options, including the services to assist them to achieve their employment related goals.
- Training/Education organisations to provide people with ABI in Tasmania with the opportunity to participate in:
  - flexible learning options (including on-line and/or self paced learning);
  - specific units of interest rather than studying to complete an entire qualification; and
  - learning environments which provide appropriate equipment to maximise learning, if required.
- The Tasmanian community to recognise the valuable contributions made by people who undertake part time and/or voluntary positions of employment.
- People with ABI to be appropriately supported in the workplace if required (accurately matched support to individual need).
- Appropriate transport options to be available to people with ABI who seek employment or education.

## **ABI & the CRIMINAL JUSTICE SYSTEM**

There is evidence to suggest that offenders with cognitive disabilities are significantly over-represented in the criminal justice system, including prisons, both nationally and internationally.<sup>2</sup>

Society has determined that a person convicted of a crime needs to be sent to prison as punishment. This assumes that the individual is capable of appreciating the consequences of their actions; for a person with ABI, their cognitive deficits could affect their ability to learn from mistakes, and may mean they are not able to learn to change their behaviour due to prison, the programs there, or from other's experiences. For these people, imprisonment only temporarily removes the person with ABI from society, to an environment that could worsen their problems.

The majority of issues raised in relation to this subject at the community consultations related to the need for increased education and awareness of brain injury in the criminal justice services of Tasmania.

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<sup>2</sup> Office of the Public Advocate, Queensland (2005). 'Issues for People with a Cognitive Disability in the Corrections System', 6-7.

- There is clearly a need for court liaison officer positions statewide, with specific awareness of issues for people with ABI, to identify people's needs and co-ordinate appropriate supports and outcomes within the justice system, as required.
- People with ABI, their family members, carers and service providers have identified the need for Tasmania to consider alternate sentencing options for people whose ABI impacts on their ability to comprehend the consequences of their actions. Alternate options would consider intensive therapy and rehabilitation rather than sentencing for first time offences.

### **Recommendations:**

- Data collection processes to be implemented which record information regarding people with ABI who are supported in justice (including prison) environments. This information can then be utilised by criminal justice staff to co-ordinate appropriate supports for offenders.
- The establishment of court liaison officer positions statewide, who have specific awareness of issues for people with ABI and are able to identify people's needs and co-ordinate appropriate supports and outcomes within the justice system, as required.
- Improved awareness and understanding of the purpose of 'ABI Identification cards' used by people with ABI (provided by BIAT) within Tasmania Police staff and the general community.
- Research and community consultation to occur to develop alternate sentencing options for people with ABI (such as intensive therapy and rehabilitation) who have limitations in their ability to comprehend the consequences of their actions.

## **RELATIONSHIPS FOR/WITH PEOPLE WITH ABI (INCLUDING SEXUALITY)**

A brain injury can have a number of consequences for an individual's sexual functioning, self image, sexuality and subsequent experiences in meaningful friendships and relationships.

- People with ABI have reported low self confidence as a significant barrier to re-establishing/forming intimate relationships following ABI.
- People with ABI have reported experiencing breakdown in friendships, relationships (including sexual partnerships) as a result of the outcomes from their brain injury. They also report changes in their ability to establish new relationships as impeded due to the physical, cognitive, emotional and behavioural issues association with ABI.

### **Recommendation:**

- The social and emotional needs of people with ABI must be recognised as a major priority in the lives of people with ABI.
- Community rehabilitation goals should incorporate a strong focus on the importance of maintaining and/or establishing new social networks, friendships and relationships for people with ABI.
- Community services to provide support, information and/or workshops specifically for people with ABI to build self confidence regarding establishment and maintenance of relationships.

## **ADVOCACY**

**Some** advocacy services that respond to the needs of people with decision-making impairments have historically avoided accepting people with ABI and have voiced little understanding of the systemic issues surrounding these people, their needs and experiences. Whilst the advocacy support for people with brain injury has increased and improved significantly in recent years, those services which are attempting to address this issue are under-resourced to do so adequately.

- There is a lack of awareness and understanding of the role of advocates, and the advocacy services which are available within Tasmania to support people with a brain injury and their families/carers.
- The Tasmanian ABI community needs clarity regarding which services are available, and their referral/access processes.

### **Recommendations:**

- The role of Advocacy services to be promoted within the Tasmanian ABI community – including distribution of information about the scope and responsibility of each of these services (in a range of formats including internet, hard copy etc). This information should be readily accessible to people with ABI, their families, carers and friends throughout the rehabilitation continuum.
- Allocation of appropriate resources for individual advocacy services for people with ABI in Tasmania to ensure their rights are recognised and respected, and assist people with ABI to voice their views in relation to decisions that affect their lives.
- Allocation of appropriate resources for effective systemic advocacy for people with brain injury.
- Allocation of appropriate resources and establishment of regional ABI Service Provider Network forums/meetings.

## **COMPLEX NEEDS**

A substantial proportion of people with ABI have a dual disability including mental health, drug and alcohol and intellectual disability (in some cases a mental illness contributed to the individual's brain injury). Service eligibility is commonly denied to these people and they 'fall through the gaps'. In Tasmania, there are limited services that cater for the needs of people with ABI who have additional clinical diagnoses such as mental health condition, drug and/or alcohol dependency or intellectual disability. These people's needs are often defined as 'complex' as it can be difficult for their support requirements to be isolated to the responsibility of one service.

- The separate administration and delivery of acquired brain injury, mental health, and alcohol and other drugs services poses major problems for a co-ordinated and integrated system of care being able to address the functional needs of a very vulnerable group of citizens.
- The inability for people with ABI to access mental health services compounds and amplifies the complexities of psychiatric and drug related disorders. In extreme cases, individuals with ABI are being inappropriately contained within the criminal justice system.

- There is a significant need for an increase in collaboration and formal partnerships between key service providers in order to adequately address the needs of people with dual diagnosis.
- There is a significant need for service providers to deliver services from an early intervention/proactive planning perspective.
- Service providers are reluctant to respond to the needs of a person who presents with complex support issues, as these people are seen to be 'resource intensive'. Whilst the Tasmanian community are aware that all services' resources are finite, this adds more weight to the plea for collaboration, so services can work together in the most efficient and effective manner to achieve outcomes for people with ABI.

### **Recommendations:**

- Increased collaboration and formal partnerships between key service providers in order to adequately address the needs of people with dual diagnosis.
- Service providers to adopt and implement models of service provision which are based on early intervention and proactive planning principles.
- Consideration of the Victorian initiative where an existing officer within all Community Mental Health Clinics is appointed as the ABI representative

## **CHILDREN & ACQUIRED BRAIN INJURY**

One of the most important differences between children and adults who sustain a brain injury is that a child's brain is still developing. In children, the injury may disrupt the development of particular areas of the brain and neural pathways which can lead to arrested or delayed development of specific skills and abilities. Damage to a young child's brain may often affect the development of global brain injury rather than producing specific deficits. Previously acquired skills may also be lost due to substantial brain damage.

Current legislation in Tasmania does not recognise acquired brain injury in persons under the age of 18. Consequently, there is little available by way of information, services and support for families of children with ABI or for educators and other service providers working with children with ABI. With the number of brain injuries being reported in Tasmania increasing each year, identification of students with brain injury is becoming an important issue.

### **Education related issues**

Children who sustain an ABI often experience difficulties returning to school after injury. Cognitive deficits not appropriately identified or responded to in the assessment process, become more obvious during adolescence and make the transition from school to employment (or further learning) extremely difficult.

- As previously identified in the Community Awareness and Education section of this Issues paper, there is clear need for an increase in the provision of information and education to staff working with children in child care and school settings. In particular, there is a limited awareness of ABI amongst staff of these services, including appropriate strategies for responding to the needs of children with ABI.

- Feedback from parents of children with ABI have identified that education and care providers often respond to their child with strategies which would be appropriate for children with 'challenging behaviours' (and no cognitive limitations) and/or intellectual disabilities.
- The fact that acquired brain injury is not recognized as an educational disability category has resulted in students with acquired brain injury developing problems in all areas of their lives, including academic, medical, social behavioural, which is reflected in developmental problems that typically require more effort and resources than would have been required by early preventative efforts. This is particularly noticeable during adolescence.

### **Specialist children's services**

- The majority of services within Tasmania for people with ABI cater specifically for adults, not children.
- There is a significant need for community based organisations to have an enhanced awareness of the issues and experiences of family members of a child with ABI (including adjustment issues for parents, siblings and the child with ABI; role fulfillment; Grief and Loss; Need for information and support; implications on family and social networks).
- There is limited Case Management and respite available to children with ABI, and their families.

### **Recommendations:**

- Identify the incidence, prevalence and issues surrounding children and young people with ABI and their carers with a view to improving the responsiveness of the service system to the needs of this target group.
- Increased awareness and understanding of ABI within the Education Department and Children's Service providers, particularly regarding how brain injury may impact on a child's ability to learn.
- Information regarding issues, outcomes and experiences regarding Acquired Brain Injury in children to be included in Child Care and Education related studies.
- Broaden awareness of/educate children's services in Tasmania about the role and resources available through BIAT and other relevant community organisations.
- Develop clear referral system for the promotion of pathways of support for children and adolescents in their transition from school to further education, community based training and/or employment.

## CONCLUSION

*“The disabilities or limitations resulting from a TBI frequently leave the individual in need of assistance in order to accomplish the basic tasks of daily living. The availability of services such as health care and rehabilitation, home and community-based support services, job training and placement, income support and education can make the difference between a wasted life and a fulfilled life in the community.*

*People with brain injuries do not require a prescribed set of services. Rather, they need the availability of a range of services that are designed to meet individual needs, are diverse and change over time. Ideally, services and supports should be flexible, allowing people with brain injuries and their families access to services when they need them and not just when the system offers them. People with a brain injury should have control over the services received. To be cost efficient, the system should allow for individuals to progress to a less restrictive environment, until they reach their maximum level of independence.”* (Excerpt from “Gaps in Service”, presented by The Texas Traumatic Brain Injury Advisory Board, March 1999)

In considering the issues raised throughout the consultation process, it would appear that much of the historic neglect of people with ABI has developed through a lack of education, particularly amongst government and non-government bodies, fuelled by the perception those in most need of support exhibit challenging behaviour.

ABI specific community based services in Tasmania do not have the resources to respond to the current need of people with ABI, let alone deal with the growing number of referrals received each year. This issue, in conjunction with a lack of experience in and knowledge of ABI amongst generic service providers, is creating a significant disadvantage for this group of people and it is not unreasonable to assume is resulting in:

- A significant financial and social cost to the community:
  - Individuals being unable to attain their maximum level of recovery resulting in a significant increase in the long term costs associated with the care and support of the individual with an ABI
  - A significant and direct impact on the level, length of time and costs associated with supporting individuals with ABI requiring support services
  - A higher level of dependence which is creating unnecessary stress on the limited resources of the families involved and resulting in higher levels of requirement for respite, support and accommodation services
  - Higher than usual incidence of family breakdown
- Inequity in availability of and access to services available to other members of the community including those with other disability types
- Inequity in access to services within the ABI population where those not in receipt of financial compensation cannot access transport, therapy and support services due to the associated costs.

It would be reasonable to expect that if education, advocacy, community based rehabilitation services and behavioural support programmes were appropriately addressed, generic services would be more willing and better equipped to respond effectively. The growing demand for services for most people with acquired brain injury could be reduced if community services were expanded to deal with the complex array of difficulties that arise beyond the acute rehabilitation setting, thereby reducing the need for more expensive intervention options at a later date.

The Brain Injury Association of Tasmania (BIAT) will continue to advocate for strategies to respond to these issues. Without effective responses, the costs to the community will continue to grow. 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 Tasmania urgently require a real commitment from the Tasmanian Government to develop a service system which addresses their current and future needs.

## **DEFINITIONS**

### **Acquired Brain Injury**

Acquired Brain Injury (ABI) is an injury to the brain that occurs after birth.

ABI is defined nationally as ‘...injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. It can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke. These impairments to cognitive abilities, sensory or physical function can be either temporary or permanent and cause partial or total disability or psychosocial maladjustment’.

*(Acquired brain injury is not to be confused with Intellectual Disability. People with an acquired brain injury do not necessarily experience a decline in their overall level of general intellectual functioning. Rather they are more likely to experience significant cognitive changes that lead to difficulty in areas such as memory, concentration and communication.)*

### **Traumatic brain injury**

Traumatic brain injury (TBI) is an acquired brain injury caused by trauma. It is often (but not always) accompanied by loss of consciousness.

### **Head Injury**

Head injury is a general term indicating damage to any part of the head, including the skin covering the skull, face or jaw, or the brain. When indicating damage to brain cells, causing temporary or permanent damage the term Brain Injury is used.



# IMPACT OF BRAIN INJURY

The number and severity of problems resulting from a brain injury will differ from person to person because each individual's brain injury varies in the extent and location of damage. The extent of some of these changes may only become apparent as time progresses.

## **Cognitive changes**

Cognition is the conscious process of the mind by which we are aware of thought and perception, including all aspects of perceiving, thinking and remembering. In general, cognition is knowledge – the way we learn and perceive the world around us.

## **Lack of insight**

People with a brain injury may have great difficulty seeing and accepting changes to their thinking and behaviour. The person may deny the effects of the injury and have unreasonable expectations about what they are able to do.

## **Memory problems**

There are many ways memory can be affected. The most common is loss of short term memory, with problems in remembering people's names or appointments, passing on messages or phone calls, or remembering details read in a book or newspaper. In therapy the person may forget what they are doing from one session to the next.

## **Poor concentration**

A very common outcome is a tendency to lose concentration or be distracted easily from what they are doing. This is usually because they are having difficulty concentrating. The person may have a short concentration span, which means they might jump from one thing to the next.

## **Slowed responses**

The person with a brain injury may be slow to answer questions or to perform tasks and they may have difficulty keeping up in conversation. Their capacity to respond quickly in an emergency may also be lost.

## **Poor planning and problem-solving**

People with a brain injury may have difficulty solving problems and planning and organising things they have to do. They may encounter trouble with open-ended decision-making and complex tasks need to be broken down into a step-by-step fashion.

## **Lack of initiative**

In spite of all good intentions a brain injury survivor may sit around at home all day long and watch TV. If the problem is severe they may need prompting just to have a shower and get dressed or to participate in a conversation.

## **Inflexibility**

People with a brain injury can be very inflexible in their thinking. They can't always change their train of thought, so they may tend to repeat themselves or have trouble seeing other peoples' points of view. They may not cope very well with sudden changes in routine.

## **Impulsivity**

People with a brain injury can be very impulsive because they may have lost the filtering system or control that makes them stop and think before jumping in. This can lead to a wide range of behavioural issues and problems with relationships and finances.

## **Irritability**

People with a brain injury tend to have a low tolerance for frustration and can lose their temper easily.. If kept waiting for an appointment they may become agitated and walk out. They may become unreasonably suspicious and paranoid.

### **Socially inappropriate behaviour**

People with a brain injury may have difficulty judging how to behave in social situations. They may walk up to strangers and start telling them about their accident, they may be over familiar with therapists or they may make inappropriate sexual advances. This area can be incredibly difficult for families or partners. In more severe cases the person will often end up homeless or in the correctional system.

### **Communication**

A broad range of social skills may be affected by a brain injury including the ability to start or take turns in conversation, interpret and respond to social cues, show interest in others, use humour appropriately, shift between topics of conversation and regulate the volume and tone of voice. People with brain injury often lose their listening skills, and may talk excessively. Accompanying memory problems may mean that they often repeat topics as well.

### **Self-centeredness**

People with a brain injury will often appear to be self-centered, and may be very demanding and fail to see other people's point of view. When this happens, resentment can build up from family members, and it is a key cause of losing friends and having trouble establishing new friendships.

### **Dependency**

One of the possible consequences of self-centeredness is a tendency for the person with a brain injury to become very dependent on others. The person may not like being left alone, and constantly demand attention or affection.

### **Emotional lability**

Just as people with a brain injury have difficulty controlling their behaviour, they may also have difficulty in controlling their emotions. They may cry too much or too often or laugh at inappropriate times, or they may suffer rapid mood changes, crying one minute and laughing the next.

### **Depression**

Depression in a person with brain injury is a very common emotional consequence that usually comes some time after the injury. Signs of depression include lack of motivation, loss of sexual drive, sleep disturbance and tearfulness.

### **Physical changes**

#### **Loss of taste and smell**

A blow to the head can cause anosmia by injury to the olfactory nerve. This nerve sits between the frontal lobe and bony protrusions from the skull and is vulnerable to trauma. A blow to the head can also cause anosmia by damage to smell processing cells in the orbito-frontal or anterior temporal lobes or by mechanical damage to nasal structures. This loss of taste and smell often leads to either lack of appetite, or obesity as the person compensates with very salty or fatty foods.

#### **Dizziness and balance**

These are very common complaints after acquiring a brain injury caused by damage to the brain stem, blood pressure fluctuations from damage to areas controlling the heart and blood flow or vertigo from damage to the inner ear.

#### **Epilepsy and seizures**

These are chronic medical conditions produced by temporary changes in the electrical function of the brain, causing seizures which affect awareness, movement, or sensation. Medication will usually control these conditions well but some lives are devastated by frequent, uncontrollable seizures or associated disabilities.

#### **Fatigue**

Sometimes called adynamia, fatigue is a disorder of motivation that typically arises after injury to the frontal lobes, particularly the dorso-lateral area. People with adynamia will experience loss of drive, indifference and placidity and may find themselves exhausted for days if they do not carefully manage their limited energy levels.

### **Headaches**

There are multiple sources of head and neck pain, both inside and outside the head. Headaches arising from a brain injury can be caused by displacement of intracranial structures, inflammation, decreased blood flow, increased muscle tone, inflammation of the thin layers of tissue coating the brain and increased intracranial pressure.

### **Visual problems**

Vision and visual functioning is often adversely affected by brain injury. Some of the more common visual systems problems include double vision, field cuts, sector losses, rapid eye movement and near-sightedness.

### **Chronic pain**

This kind of pain persists beyond the expected healing time and continues despite appropriate physical improvement in the affected area of the body. The pain can emerge as headaches, neck and shoulder pain, lower back pain and/or pain in other body areas if trauma caused the brain injury. The pain may be so intense and bothersome that the person withdraws from work, family and social activities.

### **Paralysis**

Differing degrees of paralysis can affect all parts of the body depending on which part of the brain has been injured. Effects can include poor coordination, difficulty walking, visual difficulties or weakness on one side of the body.

### **Hearing problems**

Hearing problems can occur for a number of reasons, both mechanical and neurological, particularly when the inner ear and/or temporal lobes have been damaged. Tinnitus is experienced as noises which are commonly like a buzzing, hissing or ringing in the ears. Meniere's syndrome is caused by excessive pressure in the chambers of the inner ear. Nerve filled membranes stretch which can cause hearing loss, ringing, vertigo, imbalance and a pressure sensation in the ear.

Auditory agnosia is impaired recognition of nonverbal sounds and noises but intact language function. In some cases trauma to the inner ear can cause the person to be extremely sensitive to certain noises or pitches and may not be able to tolerate many environments we take for granted.

### **OTHER PROBLEMS**

So far only the more common issues have been looked at. However there are many disorders that are less common but no less debilitating. For example, heterotopic Ossification is a secondary condition in which there is abnormal bone growth in selected joints, most commonly in the hips, shoulders, knees and elbows, usually occurring within the first nine months after injury. Chronic neuroendocrine difficulties are occurring in women some years post injury, with weight gain, thyroid disorders, changes in hair and skin texture and perceived body temperature changes. Other people with brain injury struggle with topographic dislocation, where they cannot remember how to navigate even well known environments, such as their own home or suburb.

### **MYTHS AND MISCONCEPTIONS**

A widely perceived myth is that a brain injury is simply a type of intellectual disability. People with brain injury usually retain their intellectual abilities but have difficulty controlling, coordinating and communicating their thoughts and actions.

Brain injury is often called the invisible disability. As there are frequently no outward physical signs of a disability, effects such as fatigue, lack of initiation, anger, mood swings and egocentricity may be seen simply as personality defects by family members, government policy makers and health professionals. As a result there are very few supports available for people with brain injury, and often the few supports available may be withdrawn as the disability is not recognised. It is easy to see why a brain injury can be such a devastating disability, especially when it is historically one of the most neglected when it comes to support services for people with brain injury.

The right support can achieve remarkable results. Brain Injury Associations often come across cases of people with brain injury who would otherwise be homeless or in prison, but can be integrated into the community with appropriate support.