BRAIN INJURY AUSTRALIA

Complexities of co-morbidity (acquired brain injury and mental illness) and the intersection between the health and community services systems

A Summary Paper prepared by Brain Injury Australia Inc. for the Department of Families, Community Services and Indigenous Affairs

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Introduction

Acquired brain injury (ABI) is often termed 'the invisible disability' because the nature and impact of brain injury are not well understood or acknowledged by policy makers and the community at large. This lack of understanding has resulted in a fragmented approach to program funding, policy and service development, and a high level of unmet need for individuals with an ABI and their families.

The disadvantage experienced by individuals with an ABI is compounded with the onset or pre-existence of mental health problems including a mental illness or a mental disorder. Undiagnosed and untreated mental health problems can exacerbate difficulties and jeopardise the rehabilitation of the individual potentially exposing him/her to further risk of family breakdown, social isolation, unemployment, homelessness, aggression and violence, exploitation and, in more serious situations, may lead to involvement in the criminal justice system.

Brain Injury Australia (BIA) has developed this summary paper:

- to raise awareness within government of the significant disadvantage experienced by individuals with a dual disability of ABI and mental illness;
- to identify barriers to optimum support, and
- to make recommendations to improve responsiveness and achieve optimum outcomes for this group in our community.

Definition of key terms

The following definitions inform the discussion within this paper.

Acquired brain injury

The term acquired brain injury (ABI) is used to describe all types of brain injury that occur after birth. ABI is

'…injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. It can occur as a result of trauma, substance abuse, stroke, hypoxia, infection or degenerative neurological disease. Impairments to cognitive abilities, sensory or physical functioning can be either temporary or permanent and can cause partial or total disability and psychosocial maladjustment.'[1]

Traumatic brain injury

Traumatic brain injury (TBI) is an acquired brain injury caused by an external force. This could be a blow to the head or by the head being forced to move rapidly forward or backward. It is usually accompanied by some loss of consciousness. This may be the result of a motor vehicle accident, assault, fall, or from being shaken. As a result of this blow or rapid movement, the brain may be torn, stretched, penetrated, bruised or become swollen. Oxygen may not be able to get through to brain cells and there may be bleeding.

Mental Health

Mental Health is a state of emotional and social wellbeing in which the individual can cope with the normal stresses of life and achieve his or her potential. It includes being able to work productively and contribute to community life.[2]

Mental Illness or disorders

The term mental illness is synonymous with mental disorder. A mental illness is a clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or

social abilities. These symptoms are characterised by alterations in thinking, mood or behaviour (or a combination of these), associated with distress and/or impaired functioning.[3]

Mental Health Problems

The term 'mental health problems' is used to describe a broad range of emotional and behavioural difficulties. Mental health problems encompass less severe emotional and behavioural problems, as well as 'mental disorders' or 'mental illness', which generally refer to severe and/or persistent states, and describe a clinically recognisable set of symptoms.[4]

Prevalence

While there is a general paucity of research about ABI, there are a number of published studies providing evidence of the strong association between ABI and mental illness. The studies primarily, but not exclusively, focus on individuals with TBI. It is important to note that some researchers have commented that prevalence data is likely to be an under estimate; firstly because diagnostic and assessment tools generally did not include ABI or TBI-specific measures, and secondly because the clinical presentation of ABI and mental illness can be very similar and the co-morbidity may not be recognised.

In ABI-specific research in 2006[5], the Australian Institute of Health and Welfare found that:

- Multiple disability is characteristic of the population with ABI.
    - When compared with all disability groups, people with an ABI are far more likely to have multiple conditions including mental health problems and substance abuse.
    - There is significant co-morbidity of ABI with depression, mental illness, substance abuse and other high risk situations including homelessness and involvement in the criminal justice system.

Findings from other studies provide evidence that:

- brain injury not only causes mental illness[6], but that after a brain injury an individual can have up to a four-in-five likelihood of developing a diagnosable mental illness.[7,8]
- there is a one-in-three likelihood of a client in a mental health service having an ABI[9,10],and that this compromises treatment.[11]
- TBI is the most common cause of hospitalisation in young people, and is a major cause of severe disability, with greater prevalence for men[12].
- emotional disturbances after TBI are some of the most disruptive consequences socially and occupationally.[13]
- TBI may produce a variety of neuropsychiatric problems including impaired cognition, depression, mania, affective lability, irritability, anxiety and psychosis.[14]
- there is a strong association between TBI and mood and anxiety disorders.[15] Prevalence of anxiety disorders in TBI patients may be in the order of 10-20% with post-traumatic stress disorder, obsessive compulsive disorder and generalised anxiety disorder being much more likely to occur than phobias[16]
- major depression occurs in approximately 27% of TBI patients. There is a 1.5 times higher lifetime chance of depression in TBI compared with non head-injured patients.[17]
- schizophrenia is approximately twice as common in TBI patients than in the general community[18]
- a history of TBI is a risk factor for psychiatric morbidity. The effect is greatest in young adults, and occurs up to decades subsequent to the occurrence of TBI.[19]
- a history of TBI is associated with increased symptoms of depression, anxiety, negative effect and suicidal ideation.[20]

- Hospital based studies have shown increased suicide rates following TBI that have been attributed to psychosocial disadvantage and psychiatric disorders resulting from the TBI.[21]
- Behavioural problems may occur in more than half (61.6%) of TBI patients months after injury.[22]
- An Australian estimate of the incidence of TBI based on hospital data in 1996 was 100:100,000[23]

    - However more recent studies would suggest this is increasing. For example, a study in 2004[24] reported that the incidence of TBI resulting in hospitalisation each year in NSW was approximately 126:100,000. The study also found that the incidence of TBI was most common in the age group of 15-35 years and in males.

The Consumer Experience

BIA undertook initial consultation with a number of individuals with ABI and mental illness or mental health problems, an ABI consumer self advocacy group and ABI advocacy services. The individual vignettes in this section are not intended to be 'representative' of the experiences of everyone with ABI and mental illness, but they do provide some insight into issues faced by this group. The names of the individuals and some details have been changed to protect their privacy.

It should be remembered that these experiences of mental illness are in addition to the significant impacts of brain injury. For example, cognitive impairment may mean the individual has difficulty remembering and comprehending things, learning new things, adapting to changes, solving or working through problems and organising their daily activities. This may be accompanied by personality and behavioural change, low frustration levels, poor impulse control and a range of physical conditions including epilepsy.

Those individuals who had a pre-existing mental illness prior to the onset of an ABI were more likely to receive some support from, or participate in programs of, mental health services. However some participants commented that the impact and changes arising from their ABI were often not well understood or acknowledged. Short term memory loss, an inability to concentrate and difficulty controlling emotions, particularly anger, were cited as examples of ABI-related changes that were often misunderstood or misinterpreted by staff. Other participants provided examples of the positive support they had received from mental health services, particularly when they were experiencing significant episodes of depression or needed a specialist community based program to keep them 'grounded' or socialising with others.

Annie

Annie was a survivor of severe physical and sexual abuse. Her first brain injury occurred as a pre-school age child and was abuse-related. The impact included difficult-to-control epilepsy and a learning disability. At school Annie experienced significant social and behavioural problems and was considered 'disturbed'. Her adolescence was also difficult and included bouts of depression, eating disorders and several suicide attempts. However Annie survived and carved out a life for herself despite further brain injury related to the severity of her seizures. Annie still struggles with episodic psychiatric symptoms and maintains contact with psychiatric disability support services.

"I go to women's group sometimes…when I get too depressed to work, I go a lot more."

Marco

Marco was a man in his early thirties with an ABI and a history of admissions to a metropolitan psychiatric hospital prior to the onset of his brain injury. Marco had moved to a rural area in recent years and had been admitted to the town's inpatient psychiatric ward at the local hospital because of numerous episodes of self harm and suicide attempts. There

appeared to be little understanding or tolerance of the impact of his ABI and no care plan to support him in the community after discharge. No case management was provided resulting in little continuity of care and repeated involuntary admissions. Marco was very distressed by his situation and felt that the staff at the hospital didn't understand and that he might not survive. The one thing that seemed to keep Marco going was his annual return visit to his former ABI support agency (hundreds of kilometres away) to discuss his progress and the issues he faced, particularly coping in a small town without any specialist ABI supports.

Individuals with ABI who first experienced significant mental health problems after the onset of their ABI indicated that it was extremely difficult to access mental health services; either as an individual or with the support of others. As with other dual disabilities, some people were told:

"It's your ABI (that's the problem)", "Your disability worker will know how to help you" or "You just don't fit our system".

Access to specialist mental health services around Australia, particularly acute services, appears to be dependent on a prior history of diagnosis and treatment by psychiatric services, a referral by a skilled GP or such ill-health or extremity of behaviour that the individual is considered to be a serious risk to themselves or others.

Jenny

Jenny was a woman in her twenties with ABI who was receiving support services from community-based disability organisations. When she became increasingly depressed and suicidal her support workers did not know where to go or who to approach. They assumed her problems related to her ABI.Jenny's condition deteriorated and in desperation she eventually contacted an ABI self advocacy group for assistance. After exhaustive efforts the consumer group was able to gain some short term support for Jenny, but they could not access the longer term specialist support and care she required at that time. When attempts were made to refer Jenny to a mental health service they were told:

"She has an ABI so it's nothing to do with us", She's not sick enough so it's not psychiatric" and finally "She just doesn't fit the right box".

While more extensive consumer consultation needs to occur, preliminary feedback has highlighted the negative impact of program silos which polarise support programs such as disability and mental health. Instead of a system of support and care which wraps around an individual, it is the individual who is currently required to position, jostle and manoeuvre themselves across several sectors in order to gain access to, at best, minimal levels of support and care.

Context for system planning and response in Australia

Commonwealth

There are a plethora of government agreements, plans, programs and initiatives which should provide a framework or a foundation for a planned and co-ordinated response to meet the needs of individuals with dual, multiple and/or complex needs within Australia.

1. The National Mental Health Plan (NMHP) 2003 – 2008 recognises that mental health and mental illness are on a continuum, and the Plan considers ways to improve mental health, as well as to reduce the prevalence and burden of mental health problems and mental illnesses.

    - Priorities under the first and second NMHP include: strengthening the relationship between mental health services and the general health sector, and linking mental health services with other sectors
    - An additional priority under the second NMHP is the development of partnerships in service reform, quality and effectiveness of service delivery

- The NMHP also acknowledges that people with co-morbid conditions, particularly co-morbid substance use disorders, but also intellectual disability and physical illness and disability, often have complex needs that require a co-ordinated response from multiple service sectors.

Comment: No reference is made to ABI in the NMHP when considering disability groups with dual or multiple disabilities or needs. In addition, there is currently little demonstrable evidence of strategies which link mental health services with other sectors and contribute to 'a co-ordinated response from multiple service sectors', despite the NMHP being in its fifth year of implementation.

2. The Commonwealth State Territory Disability Agreement (CSTDA) is a funding agreement between the Commonwealth and the States and Territories of Australia to support the needs of people with a disability.

   - The new CSTDA is yet to be finalised, but priority has been given to accommodation and respite services.
   - There is some additional funding in the next agreement for strengthening and building the capacity of the National Disability Advocacy Program. This acknowledges, in part, the unacceptably high level of unmet need and access issues experienced by many people with a disability.

   Comment: In its submission to the Senate Committee Inquiry into the CSTDA in 2006 BIA successfully argued that the needs of individuals with an ABI were under resourced resulting in high levels of unmet need. BIA also raised the issue of dual disability of ABI and mental illness, but mental illness falls outside the parameters of the CSTDA. Health and Disability are located in separate departments with different Ministers holding respective portfolio responsibility.

3. COAG Mental Health Initiatives 2006-2009 provided significant levels of new funding for community based mental health services which included respite, support and mentoring.

   - Eligibility criteria were to be determined, but a commitment was given to functional rather than clinical criteria.

   Comment: While the target population is individuals with significant mental health problems, the respite component made specific provision for access by individuals with an intellectual disability with no clear rationale as to their inclusion. BIA welcomed the new initiatives and was optimistic that there were significant gains for individuals with an ABI and co-morbid mental illness or disorders. Given the difficulty this population faces gaining access to assessment for mental health services, BIA was heartened by a commitment to functional need rather than a requirement in the first instance of a formal clinical diagnosis. In a spirit of collaboration and goodwill, BIA met with the three managers responsible for the implementation of the COAG Initiatives. We were advised that the implementation team was established in FaCSIA, rather than Health and Aged Care, to ensure a less clinically focussed approach for the new initiatives.

   The COAG managers acknowledged the difficulties they were experiencing in knowing how to go about establishing criteria for dual disability, but indicated a willingness to work with BIA and an expert group to be established by BIA to assist the development of ABI-Mental Illness eligibility criteria. BIA secured the support and willing participation of three eminent dual disability specialists within Australia, but no response has been received to date. Details of the Expert Clinical Group were provided to the Mental Health Branch, FaCSIA in January 2007. Similarly there has been no response to follow up telephone calls and emails. Support was sought from the Disability Branch and BIA awaits advice on the outcome of discussions between the Disability Branch and Mental Health Branch on this matter.

States/Territories

With only one exception, the segregated program and funding silos identified at the Commonwealth level of government are mirrored at the state/territory level. Even when Health and Community Services are housed in the one Department, they will generally have separate Ministers and discrete program branches or divisions. Victoria is leading the way in its cross program approach to ABI and mental illness.

1. Victoria - ABI-Mental Illness Strategy has lead to the cross program funding of a specialist statewide dual disability assessment and treatment service (CBDATS). Key steps in the strategy included:

    - Agreement to prioritise this issue and develop a collaborative partnership between Disability Services Division and the Mental Health Branch
    - Development of an Issues Paper for consultation: 'ABI and Mental Illness'
    - Development and implementation of an ABI and Mental Illness Protocol between mental health and other services

2. Victoria – The Multiple and Complex Needs (MACN) Initiative is a whole-of-government strategy which includes a partnership between Disability Services, Mental Health, Drug Treatment Services, Justice, Housing, Office for Children and Corrections to provide co-ordinated planning, care and regular review for individuals with multiple and complex needs considered to be at high risk.

    - The Initiative is open to people from 16 years to 65 years of age
    - Eligibility criteria relates to appearance (not necessarily formal diagnosis) of two or more disabilities plus additional risk factors
    - A higher than anticipated percentage of clients are individuals with ABI with one, two or three co-morbidities; most commonly mental illness and substance abuse

Whilst it is early days, BIA understands that Queensland is involved in service development and training in relation to ABI and mental illness.

Summary discussion

People with acquired brain injury fall into a chasm. They either do not 'fit' the criteria of available programs or the programs offered are inadequate or inappropriate. People with a dual disability of ABI and mental illness are often refused access and treatment by mental health services throughout Australia. Specialist mental health services in Australia are increasingly characterised by entry or eligibility criteria prioritising psychosis and severe mental illness. This is combined with widely held perceptions of a crisis driven system which makes little provision for early identification of risk and timely intervention to avoid escalation of symptoms and unnecessary hospitalisation.

If ABI consumers do gain access to a mental health service they may receive treatment for their psychiatric symptoms (assuming an appropriate diagnostic assessment has been undertaken), but their ABI may not be considered a relevant factor in planning their ongoing treatment, management and psychosocial rehabilitation. In fact, there is some evidence to suggest that staff in many mental health services are unaware that a significant percentage of their clients may have an ABI.

This raises several issues about the responsiveness and adequacy of existing service systems which support individuals with an ABI and a mental illness or mental health problems or with other complex or multiple needs. Individuals do not live their lives neatly compartmentalised in the way funding and program structures would seem to imply. Artificial program and funding boundaries continue to create barriers to effective and responsive planning and service provision for some of the most disadvantaged members in our community. The lack of a holistic, social model of health and wellbeing means that it is the individual (and their carers) who must expend energy trying to find the right doors to knock

on, and it is inevitably the individual who suffers poor health outcomes and unacceptable levels of risk because of this fragmentation. Further, the lack of proactive planning and program co-ordination is not cost effective; either in human or financial terms. While the need for collaborative partnerships has been clearly demonstrated, the Disability and Mental Health systems do not intersect in any meaningful way, and there is little discernible evidence to suggest this has been a priority for government and government departments.

Who are the ABI champions within government? Leadership is required to ensure that, over time, a whole-of-government strategy is developed for planning and responding to the needs of individuals with dual or multiple disabilities. A commitment to the establishment of cross program and inter-departmental partnerships and collaboration is an obvious starting point in redressing the current inequity and disadvantage experienced by individuals with an ABI. There are some positive precedents set in recent years where significant commitment and investment in other areas of dual disability such as mental illness and substance use or mental illness and intellectual disability, have fundamentally changed the face of service provision and support for these populations.

This investment has contributed to new research and learning which in turn has informed effective workforce development which is integral to effective cross program service development. A demonstrable commitment to shared responsibility within government directly influences the culture of the service system and in effect models and provides permission for innovation and best practice. This shared approach to policy, planning and service development will ultimately drive change at the coalface. In terms of the needs of individuals with dual or multiple disability, one example would be the promotion of co-ordinated case or care plans which detail the role of each of the multiple service provider organisations involved, establish agreed communication processes including active participation of the individual with dual disability, and which regularly convene to review progress and resolve emerging issues. This level of co-ordination and multidisciplinary cohesiveness is lacking at present. Effective implementation of this strategy could offset a number of risk factors and prevent avoidable escalation of crisis or illness.

Whatever strategies or frameworks are developed, the bottom line from BIA's perspective is improved responsiveness to and optimum outcomes for individuals with an ABI.

Recommendations

1. That the Disability Branch within the Department of Families, Community Services and Indigenous Affairs meet with representatives of Brain Injury Australia to discuss this issue further.

2. That senior management of the Disability and Mental Health Branches within the Department of Families, Community Services and Indigenous Affairs meet to consider strategies to ensure individuals with an ABI-mental illness dual disability are not disadvantaged or excluded from the continuing implementation of the COAG Mental Health Initiatives.

3. That senior management of the Disability Branch within the Department of Families, Community Services and Indigenous Affairs meet with their peers in Mental Health in the Department of Health and Aged Care to consider options and strategies for more effective cross program policy, planning and service development for this disability population.

4. That fundamental to any policy or program development is active consultation with individuals with an ABI, their families and those groups and organisations which represent them and advocate on their behalf.

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