

# EXECUTIVE SUMMARY

The Challenging Behaviours Project was devised to address gaps in the current knowledge base about challenging behaviours after traumatic brain injury (TBI). Data was collected separately for adults and children and is reported separately.

The collection of this data informs the development of a model of care for the management of challenging behaviour clients after sustaining a TBI. The adult report describes a two-stage study undertaken by the Brain Injury Rehabilitation Directorate (BIRD), Agency for Clinical Innovation (ACI) to collect data on prevalence, course, co-morbidity and burden of challenging behaviours in adult clients living in the community and involved with the NSW Brain Injury Rehabilitation Program (BIRP).

The results of this study informed the development of eight key principles for the BIRP to integrate into their current model of service delivery and 41 recommendations for changes or enhancement to the existing model of service delivery for clients with, or at risk of, demonstrating challenging behaviour.

The implementation of a Behaviour Support and Development Service within the BIRP is identified as the most practical way to ensure these principles and recommendations are adopted and implemented.

## BACKGROUND – THE NSW BRAIN INJURY REHABILITATION PROGRAM (BIRP) AND THE BRAIN INJURY REHABILITATION DIRECTORATE (BIRD)

The BIRP is a state-wide specialist rehabilitation service for people who have sustained a traumatic brain injury. The network consists of 11 adult and three paediatric units offering inpatient, transitional living and community services.

The BIRD was established as an ACI clinical network in 2002 and utilises the 11 adult and three paediatric BIRP services to identify how and where improvements are needed for delivering safer and better care by incorporating clinician and consumer involvement.

Each BIRP service submits electronic demographic and clinical data for all client admissions to the BIRD for reporting. The Challenging Behaviours Project was able to access this information for all adult admissions and was able to involve clinicians from each adult service in the study to collect additional information relating to challenging behaviours.

## METHODOLOGY

The Challenging Behaviours Project involved data collection in two stages from February 2007 to December 2009. The first stage of the project involved quantitative data collection from BIRP clinicians about 659 clients who met criteria for inclusion in the study. Clients included in the study had a primary traumatic brain injury diagnosis; were aged between 18 and

65 years; were active clients of the BIRP (i.e. had at least three occasions of service six months prior to recruitment into the study); and were living in the community. Clinical informants completed a battery of surveys about each client's behaviour; medical and psychosocial problems; care and support needs; level of participation; and level of servicing.

The second stage of the project involved a qualitative case review of 28 clients known to have challenging behaviours from 10 of the adult BIRP services. This qualitative review involved a detailed (one and a half-hour) semi-structured interview with a clinical informant about the client's behaviour and how they were managed. Medical records were also accessed to glean further information about each client's behaviour.

## RESULTS

### Prevalence

The project found the prevalence of challenging behaviour after TBI to be high; 53% of clients in the study met criteria for challenging behaviour. The most prevalent challenging behaviour was inappropriate social behaviour (30%), followed by verbal aggression (26%); adynamia/lack of initiation (23%); perseveration/repetitive behaviour (13%); physical aggression against others (11%); physical aggression against objects (7%); physical acts against self (5%); inappropriate sexual behaviour (4%); and absconding/wandering behaviour (3%).

### Course

The project found a stable course of behaviour for the majority of clients included in the study, in that 75% of adult clients did not change their behavioural classification (challenging versus non-challenging) over a three-month follow-up period. The remaining 25% of clients changed their classification over the three months: 11% developed challenging behaviour not present initially and 14% improved in their behaviour over a three-month follow-up. Overall, the prevalence of challenging behaviour remained unchanged over the three-month period.

### Co-morbidity

Problems with drug and alcohol use and mental health were found to be significantly related to the presence of challenging behaviour. The project found that clinically significant pre-injury alcohol problems increased the odds of challenging behaviour by a factor of two and that current moderate to severe drug and alcohol use increased the odds for challenging behaviour by a factor of four. Increasing levels of depression and other mental

Thematic clusters associated with challenging behaviour (Figure 19)

#### Client characteristics

Themes included drug/alcohol abuse, mental health co-morbidity; pre-morbid health and psychosocial difficulties; lack of client insight and motivation; and level of client impairment and disability.

#### Family/carer characteristics

Themes included lack of support, inconsistent responses and negative attitudes of family and carers contributing to challenging behaviours.

#### Environmental (non-family) factors

Themes included lack of co-ordinated care, accommodation issues, lack of services in remote/regional areas, limited psychological support, few respite options and lack of supported participation contributing to challenging behaviours.

#### Medical issues

Themes included lack of support for co-morbidities maintaining challenging behaviours, and complex medical issues contributing to problematic behaviour.

health problems increasing the odds for challenging behaviour by a factor of three and eight respectively. In addition to the above co-morbidities, other factors were also shown to have a significant bearing on the presence of challenging behaviour, such as level of cognitive impairment and disability.

#### Burden

The burden of challenging behaviour was demonstrated in the study in terms of reduced participation, high levels of care and support need, increased demand on services and elevated level of unmet service need.

Only 5% of clients with challenging behaviour had good levels of participation compared with 54% and 49% having somewhat limited to very poor participation levels respectively.

Only 11% of clients with challenging behaviour had no care and support needs compared with 43% and 46% needing less than daily or daily care and support respectively.

In terms of burden on service delivery, with the exception of social work and psychology services, this project showed that there

## DEVELOPMENT & MAINTENANCE OF CHALLENGING BEHAVIOURS

## CONSEQUENCES OF CHALLENGING BEHAVIOUR

Themes included such things as family/carer burn-out, increased contact with criminal justice system and exclusion from services and participation opportunities.

was no difference in the number of BIRP professional services provided to challenging and non-challenging behaviour clients. Instead, challenging behaviour clients were shown to place greater demand on non-BIRP services than their non-challenging counterparts. This greater level of servicing to challenging clients was insufficient, as these clients continued to demonstrate significantly greater unmet need for services compared with non-challenging behaviour clients for 15 out of 16 areas of service need. Furthermore, the project showed that remote and regional challenging behaviour clients were more disadvantaged in the level of services they received and level of unmet need compared with urban challenging behaviour clients.

### Themes associated with challenging behaviour

The qualitative review of 28 BIRP clients' uncovered 24 themes associated with challenging behaviour. These themes could be clustered into five categories. Four of these clusters represented factors resulting in the development and maintenance of challenging behaviour and another cluster described the consequences of challenging behaviour (see Figure 19 on p28).

The Challenging Behaviours Project found a high prevalence of challenging behaviour in the active BIRP caseload and this prevalence was stable over time. These results reveal that the BIRP needs to treat challenging behaviour as a matter of core business requiring implementation of long-term management strategies.

The data from the quantitative arm of the project revealed that client cognitive impairment, disability, mental health and drug and alcohol co-morbidity were significant predictors of challenging behaviour prevalence. The qualitative data supported the importance of these factors but moreover also revealed a more complex scenario whereby other client, family/carer, medical and environmental issues contributed to the development and maintenance of challenging behaviours after TBI. There were also notable consequences of challenging behaviour such as increased contact with police and the criminal justice system and exclusion from participation. It is important to note, however, that lack of participation was not only a consequence of challenging behaviour but also contributed to the development and maintenance of challenging behaviour, particularly when there was no meaningful, supported participation opportunities provided to clients with a TBI.

Given the variety of problems associated with challenging behaviour, it is not surprising to find that challenging behaviour clients were in greater need of care and support than clients who did not have challenging behaviour. Somewhat surprisingly non-BIRP agencies provided relatively more services to challenging than non-challenging clients, whereas the BIRP provided an equivalent amount of services to both groups. The project also found geographical inequity in the provision of

services around the state, with BIRP and non-BIRP services alike more likely to be received by challenging behaviour clients in urban areas than in regional and remote areas.

The results of the Challenging Behaviours Project led to the development of eight principles considered important in the implementation of a Model of Care for clients with challenging behaviour after sustaining a TBI. These principles are presented below along with recommendations for service enhancements and changes that would allow the BIRP and non-BIRP agencies to implement them.

### PRINCIPLE 1:

Early identification and intervention is required to prevent challenging behaviours becoming entrenched patterns of client functioning

#### Recommendation 1:

BIRP services to have a system of assessment and monitoring for TBI clients that will allow for the early identification of challenging behaviours and the early implementation of behavioural management plans. Where appropriate, this system of assessment and monitoring should include standardised, validated instruments.

#### Recommendation 2:

BIRD needs to develop a practice guideline for assessment of pre-morbid and current issues which will aid in the assessment of risk of clients developing challenging behaviour in the community.

#### Recommendation 3:

BIRP services need to evaluate the effectiveness/outcomes of behavioural management plans so they can promptly and objectively determine when plans are or are not working.

#### Recommendation 4:

BIRP services need to develop and implement formal protocols for undertaking systematic case review of clients whose challenging behaviours have not changed despite behavioural management approaches, so that weaknesses in approaches or environments can be identified and new strategies initiated.

## **PRINCIPLE 2:**

An interdisciplinary approach to managing challenging behaviours is required at all levels and types of impairment and disability

### **Recommendation 5:**

BIRP to ensure an interdisciplinary approach to the management of challenging behaviour where the psychosocial environment and/or cognitive and physical functioning of the client is recognised as contributing to challenging behaviours.

### **Recommendation 6:**

There is a need for BIRD and BIRP services to understand the relative contribution of non-BIRP agencies in the provision of services to clients with challenging behaviour.

## **PRINCIPLE 3:**

Clients require adequate level of care, support and environmental modification

### **Recommendation 7:**

BIRP needs to develop a clinical pathway for the transition of clients with challenging behaviour from the inpatient setting to family-based community support and care.

### **Recommendation 8:**

There is a need to increase in-home services so that families can sustain their role in providing care and support to clients.

### **Recommendation 9:**

BIRP needs to provide supervision and support to families so they can provide an adequate environment to manage a person with cognitive and disability issues.

### **Recommendation 10:**

Service responses involving carers and clinicians need to be developed for the small group of people so impaired/disabled that they require lifelong 24 hours a day, seven days a week support and supervision.

### **Recommendation 11:**

There is a need to increase available community-based alternatives to family care so as to provide the stable living environment some clients need to manage their behaviour whilst also maintaining family involvement.

### **Recommendation 12:**

All ancillary carers should be required to undertake training before working with TBI clients.

### **Recommendation 13:**

Ancillary services should have a formal personnel management structure that encourages carers to follow treatment guidelines provided by BIRP.

## **PRINCIPLE 4:**

Consideration must be given to the medical, psychosocial and environmental context of clients' challenging behaviours (i.e. a whole-of-client approach)

### **Recommendation 14:**

BIRP staff need to advocate for, access and provide support for individual clients to access Drug & Alcohol and Mental Health services.

### **Recommendation 15:**

BIRD needs to develop and support state-wide education programs for Drug and Alcohol services and Mental Health services staff to increase awareness of issues relevant to the TBI client population and improve the ability of these services to support clients with TBI.

### **Recommendation 16:**

BIRD needs to develop and support state-wide education programs for NSW Police to increase their awareness of issues relevant to the TBI client population and promote appropriate police and legal responses.

### **Recommendation 17:**

BIRD needs to provide practice guidelines for access to appropriate public housing solutions for people with challenging behaviours at risk of injury to self or others, and to foster maintenance of public housing.

### **Recommendation 18:**

BIRD needs to develop pathways for clients with elevated risk for challenging behaviour to access non-BIRP service systems (e.g. avocational programs).

**Recommendation 19:**

BIRP needs to explore the current situation for respite and assess the capacity for BIRP to provide appropriate respite services.

**Recommendation 20:**

BIRD need to liaise with the Brain Injury Association of NSW (BIA) who is the consumer advocacy service to explore options for improved access to appropriate respite services including emergency respite for clients, to improve community living solutions and improve access to services to meet the assessed needs of adults with TBI.

**PRINCIPLE 5:**

There is a need for equitable access to all services throughout the state, based on need

**Recommendation 21:**

BIRP services that cater for remote clients need to have the option of providing a transitional living program (seven days per week), develop linkages within the network and/or for resources to be increased to enable staff from these services to travel to remote areas when there is no opportunity for program admission.

**Recommendation 22:**

All BIRP services need to incorporate the management of family and ancillary carer issues in working with clients by including social workers and/or case managers with these skills in the team.

**Recommendation 23:**

There is a need to increase psychological services within BIRP.

**Recommendation 24:**

There needs to be greater resources within BIRP so that remote/regional clients are able to access specific professional services (e.g. occupational therapy, diversional therapy, speech pathology, physiotherapy, clinical psychology, clinical neuropsychology).

**Recommendation 25:**

BIRP needs to increase the use of technology for clinical service consultations (e.g. rehabilitation specialists, clinical psychologists) and management of clients in remote parts of the state via local health service providers.

**PRINCIPLE 6:**

Client-centred communication pathways must be established and maintained to ensure smooth and timely delivery of all services needed by clients

**Recommendation 26:**

BIRP to work collaboratively with D&A and Mental Health Services to ensure that clients receive the services they need. This could include establishing local service agreements and interagency case conferencing for management of complex clients.

**Recommendation 27:**

BIRP to increase understanding of the monitoring process of people on court-ordered bond breaches to increase the effectiveness of these strategies in managing challenging behaviour.

**Recommendation 28:**

BIRP staff to identify clients in contact with police to liaise about strategies to prevent and/or manage challenging behaviour resulting from TBI and prevent escalation.

**PRINCIPLE 7:**

Evidence-based treatments for challenging behaviour need to be utilised

**Recommendation 29:**

BIRD should develop standard challenging behaviour education programs (e.g. workshops) for family and ancillary services involved in the care of clients with TBI.

**Recommendation 30:**

Continue use of TLU/inpatient units to interrupt difficult behaviour patterns to enable behaviour change to be initiated and then that change to be generalised into the family environment where the family arrangement has been identified as sustainable.

**Recommendation 31:**

BIRD to implement standardised education for all staff about best practice and the knowledge/skills required to manage challenging behaviour.

**Recommendation 32:**

There is a need to increase interdisciplinary-based training of behaviour management principles within BIRP.

## PRINCIPLE 8:

### The community and social participation of TBI clients needs to be promoted

#### **Recommendation 33:**

There needs to be a planned approach to the assessment and implementation of meaningful participation for clients of all ages and different levels of disability.

#### **Recommendation 34:**

Resources need to be allocated to enable BIRP to provide education and ongoing consultation to facilitate client engagement in community and leisure activities.

#### **Recommendation 35:**

BIRP needs to develop a process to enable the engagement of friends of clients from the early stages of rehabilitation. However, care needs to be taken so that the dynamic of the relationship between the client and his/her friends is not changed by the rehabilitation process.

#### **Recommendation 36:**

BIRP needs to facilitate the process for clients to develop new social links if clients become isolated and old links are at risk of withdrawal.

#### **Recommendation 37:**

BIRP needs to incorporate the use of social technologies to promote the social links of clients.

#### **Recommendation 38:**

There needs to be an increased availability of resources including care, transport and financial support to enable clients to participate in meaningful community and leisure activities.

#### **Recommendation 39:**

There is a need for Local Health Districts to allow BIRP staff to access social technologies that will promote clients developing and sustaining social networks.

#### **Recommendation 40:**

There needs to be an increased capacity of disability and generic leisure and recreation service providers to accommodate people with TBI and challenging behaviour.

## IMPLEMENTATION OF THE PRINCIPLES

### The scope of the above recommendations requires a planned and integrated approach to implementation

#### **Recommendation 41:**

It is suggested that the most practical and efficient way to effectively implement the principles into the current BIRP model of care would be for BIRP to establish a Behaviour Support and Development Service.

To improve the current model of care in the NSW BIRP this behaviour support and development service would initially focus their efforts in more remote parts of the state where there is currently little or no behavioural management support. This would reduce variation between services and it can be expected to have a greater education and training role in BIRP units that currently have adequate psychological support.

The Behaviour Development and Support Service (BSDS) will require additional resources to enable an expansion of the scope of the current NSW BIRP model of care to provide intensive behaviour support to individuals within everyday living situations. This program will provide a higher level of behaviour support than is currently available for intensive management of behaviour to achieve positive behaviour change in different environments. This will include:

- Assessment of needs of challenging behaviour clients
- Development of behaviour management plans
- Intensive program implementation for mentoring in certain circumstances
- Support and supervision to families, ancillary carers and BIRP staff implementing behavioural management
- Development and support of participation opportunities for clients with challenging behaviour
- Education and training to families, ancillary carers and BIRP staff
- Education and training of other non-BIRP service providers.

It will be essential for the behaviour development and support service to be staffed by clinical psychologists and/or clinical neuropsychologists for the development and implementation of behavioural management strategies and overall management of the service. Social workers will be required to assist and support this client group with known complex psychosocial and family issues. It is also acknowledged that other professions which have knowledge and experience of this complex client group may also be integral to the provision of psychosocial and family support services eg case managers, therapists and rehabilitation specialists.

The recommended BSDS will provide an organisational structure to ensure the implementation of the principals and recommendations to improve outcomes for clients and families.