ACI NSW Agency for Clinical Innovation

NSW Brain Injury Rehabilitation Program

CHALLENGING BEHAVIOURS PROJECT: ADULTS

Using the analysis of prevalence, course, co-morbidity and burden to inform the model of care

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The ACI was established by the NSW Government as a board-governed statutory health corporation in January 2010, in direct response to the Garling Report into Acute Care Services in NSW Public Hospitals. Building on the valuable work carried out by the Greater Metropolitan Clinical Taskforce (GMCT) and its predecessors. The ACI uses the expertise of its clinical networks to develop evidence-based recommendations to improve patient care within the NSW health system.

For further details on the ACI visit:
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ABBREVIATIONS

ABI	Acquired Brain Injury
ADL	Adynamia/Lack of Initiation (scale of OBS)
BIA	Brain Injury Association of NSW
BIRD	Brain Injury Rehabilitation Directorate
BIRP	Brain Injury Rehabilitation Program
BIRS	Brain Injury Rehabilitation Service
CANS	Care and Needs Scale
CBP	Challenging Behaviours Project
D&A	Drug and Alcohol
DRS	Disability Rating Scale
GCS	Glasgow Coma Scale
HoNOS-ABI	Health of the Nation Outcome Scale – ABI version
ISB	Inappropriate Sexual Behaviour (scale of OBS)
ISOC	Inappropriate Social Behaviour (scale of OBS)
MBA	Motorbike Accident
MH	Mental Health
MVA	Motor Vehicle Accident
NSW	New South Wales
OAS	Overt Aggression Scale
OBS	Overt Behaviour Scale
OOS	Occasions of Service
PAO	Physical Aggression against Objects (scale of OBS)
PAP	Physical Aggression against other People (scale of OBS)
PAS	Physical Aggression against Self (scale of OBS)
PR	Perseverative/Repetitive Behaviour (scale of OBS)
PTA	Post-traumatic Amnesia
SPRS	Sydney Psychosocial Reintegration Scale
TBI	Traumatic Brain Injury
TLP/TLU	Transitional Living Program/Unit
VA	Verbal Aggression (scale of OBS)
WA	Wandering/Absconding Behaviour (scale of OBS)
WHO	World Health Organisation

FOREWORD

The ACI's Challenging Behaviours Project addresses an important aspect of one of the more difficult and costly issues for the health system and the community - the management of patients with Traumatic Brain Injury (TBI) and challenging behaviour.

The ACI's Brain Injury Rehabilitation Directorate (BIRD) worked with the NSW Brain Injury Rehabilitation Program (BIRP) clinicians and consumers from the 14 specialist brain injury units to investigate the prevalence, course, burden and co-morbidities of challenging behaviour associated with TBI and to identify how to improve outcomes for patients and families.

The project addressed the needs of adults and children separately.

Between February 2007 and December 2009 the Adult Challenging Behaviours Project (CBP) collected information on 659 clients aged between 18 and 65 years with a primary diagnosis of TBI and completed a qualitative case review of 28 clients from 10 adult BIRP Services

The results suggest changes to the model of care to include the need for better early detection of challenging behaviour to enable intervention before problems become entrenched.

The project developed eight key principles to guide clinical practice, and 41 recommendations for an improved model of care for clients with, or at risk of demonstrating, challenging behaviours.

There are around 2,500 new cases of moderate or severe TBI in Australia each year - most frequently caused by motor vehicle accidents, other collisions, falls, and assaults.

The ACI project found the prevalence of challenging behaviour after TBI to be high, affecting more than half (51%) of the adult clients involved.

TBI can cause long term physical and neurological disability and significantly higher risk of premature death, but it is the emotional, behavioural and social consequences of TBI that cause the most distress to families and patients.

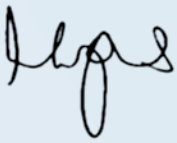
In addition to personal and family devastation, the total cost to the Australian community through direct care and lost productivity has been estimated by Access Economics (2009) at more than $8.6 billion a year. Almost two thirds of the cost is shouldered by individuals and families either directly or through insurances.

The ACI project found that there is a complex interaction between medical, psychological, social and environmental factors that contribute to the development of challenging behaviour after TBI and that an integrated model of care is, therefore, required.

This major ACI project, led by clinicians and drawing on the hands-on knowledge of doctors, nurses, allied health professionals and consumers, offers practical solutions to real problems facing individuals, families and health services across NSW.

We recommend the report to you and welcome any suggestions you may have for further improvements in future.

Dr Nigel Lyons



Chief Executive

Agency for Clinical Innovation

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.

DEVELOPMENT & MAINTENANCE OF CHALLENGING BEHAVIOURS

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

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.

INTRODUCTION

Challenging behaviours are recognised as one of the most disabling consequences of traumatic brain injury (TBI) and produce some of the most complex challenges in post-injury management.

In the literature, challenging behaviours have been associated with poor levels of return to work (Ezrachi, Ben-Yishay, Kay, Diller & Rattock, 1991); exclusion from needed services (Watson, Rutterford, Shortland, Williamson & Alderman, 2001); increased staffing costs for agencies managing such clients (Guercio & McMorrow, 2002); unwanted admissions to inappropriate institutional care (Gardner, Bird, Maguire, Carreiro & Abenaim, 2003; Manchester, Hodgkinson & Casey, 1997); and significant distress for family and staff exposed to such behaviours, as well as for the person with TBI (Ergh, Rapport, Coleman & Hanks, 2002; Hall, Karzmark, Stevens, Englander, O'Hare & Wright, 1994; Marsh, Kersel, Havill & Sleigh, 2002).

There is evidence that the course of these behaviours can persist for many years post-injury and even worsen over time (Johnson & Balleny, 1996; Thomsen, 1992). Despite these well known problems, surprisingly few studies, in Australia or internationally, have examined the prevalence of challenging behaviours within the TBI population, factors associated with challenging behaviour or burden of such behaviours in community settings. The Challenging Behaviours Project (CBP) was devised to address gaps in the literature by addressing the following four aims:

1. To establish the prevalence of challenging behaviour of people with TBI
2. Examine the course of challenging behaviour over a three-month follow-up
3. Determine the major co-morbid factors related to challenging behaviour
4. Examine the personal, carer and service burden of challenging behaviour

The CBP was important for the following reasons:

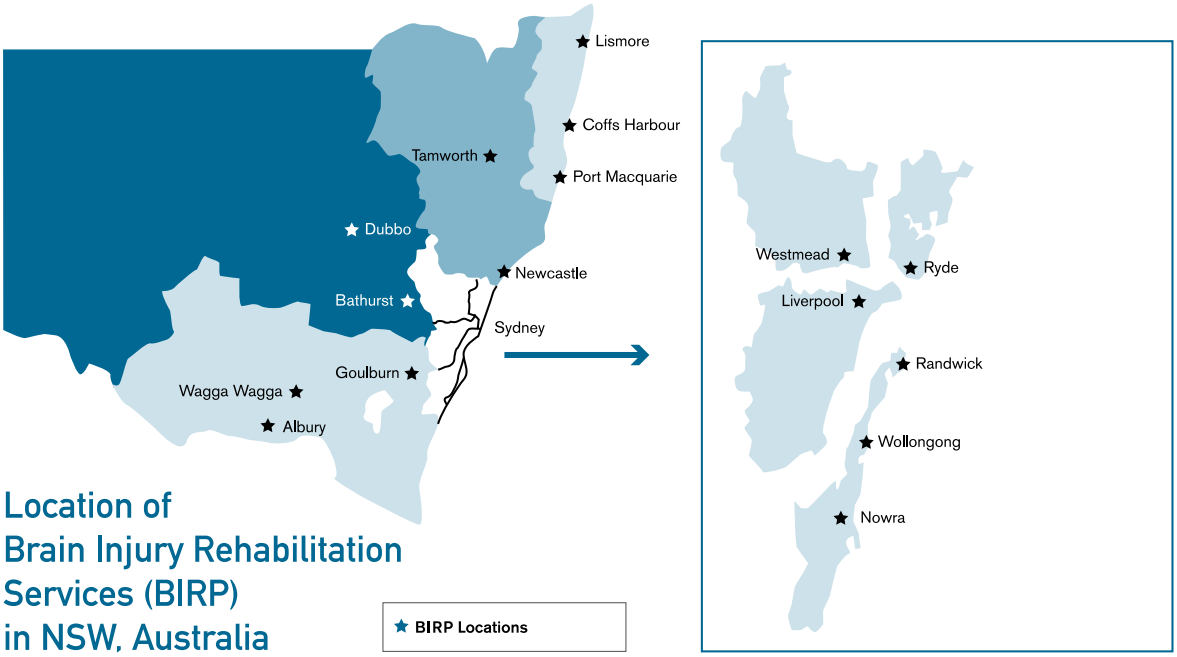
- Challenging behaviour was identified by the Brain Injury Rehabilitation Program (BIRP) as one of the top state-wide priorities requiring urgent attention
- To create an evidence base for coordinated state-wide management of challenging behaviours among people with TBI that will have flow-on effects in terms of improved levels of community integration and quality of life
- To address the expressed needs of staff within the Brain Injury sector for greater training, support and service options in the management of such behaviours
- To address the stress of family members who bear the brunt of such behaviours, and would therefore benefit from greater training, support and service options
- To provide an opportunity for NSW to show national and international leadership in the management of such behaviours, particularly in documenting their prevalence, course and co-morbidity, quantifying the associated level of burden and producing a coordinated model of care for the management of such behaviours.

Context of current study

Approval and financial support to undertake the Challenging Behaviours Project was provided by the NSW Agency for Clinical Innovation (ACI). The ACI is a board-governed statutory health corporation that reports to the NSW Minister for Health and the Director-General of NSW Health. The ACI has established 24 clinical networks in NSW that engage front-line clinicians and consumers in continuous clinical redesign to improve patient care and to reduce inappropriate clinical variation.

The Brain Injury Rehabilitation Directorate (BIRD) was established as a clinical network in 2002 and utilises the existing 11 adult and three paediatric services that make up the NSW BIRP to identify how and where improvements are needed for delivering safer and better care.

Figure 1: Locations of individual BIRP services in NSW[1].



The NSW BIRP provides inpatient, transitional and community services. Each BIRP service submits electronic demographic and clinical data for client admissions to BIRD for reporting. The CBP was able to access this information for all adult admissions to the NSW BIRP and involve clinicians from each service in the study.

[1] Newcastle and Westmead have separate adult and paediatric BIRP services. The third paediatric service is in Randwick.

METHODS

Sample

The sample for this adult study was recruited from the 11 adult services encompassed in BIRP. This included five metropolitan services in Sydney, Wollongong and Newcastle and six additional services in other parts of the state (see Figure 1). The following criteria were used to identify BIRP clients for inclusion into the study. Clients had to:

- Be community clients not inpatients
- Have had at least three occasions of service over the six months prior to recruitment into the study
- Be between 18 and 65 years of age
- Have sustained a primary traumatic brain injury (TBI)

Approval to undertake this study was provided by the Greater Western Area Health Service Human Ethics Committee, and relevant site-specific approval to undertake this study was provided by each of the services involved.

Measures

The measure used in the CBP to assess challenging behaviours was the Overt Behaviour Scale (OBS). The OBS is a well validated instrument for use in the TBI population and has been shown to capture over 90% of challenging behaviours in this group (Kelly, Todd, Simpson, Kremer & Martin, 2006). The OBS assesses nine categories of challenging behaviour: verbal aggression, physical aggression against objects, physical acts against self, physical aggression against other people, inappropriate sexual behaviour, perseveration/repetitive behaviour, wandering/absconding, inappropriate social behaviour and adynamia/lack of initiation.

The OBS requires respondents to rate the severity, frequency and perceived impact of each of the nine types of behaviours. Another four standardised and validated measures were used to collect additional information about each client, including:

- Disability Rating Scale (DRS; Rappaport, Hall, Hopkins, Belleza & Cope, 1982)
- Health of the Nations Outcome Scale – Acquired Brain Injury version (HoNOS-ABI; Wing, Beevor, Curtis, Park, Haddon & Burns, 1998)
- Sydney Psychosocial Reintegration Scale (SPRS; Tate, Pfaff, Veerabangsa & Hodgkinson, 2004)
- Care and Needs Scale (CANS; Tate, 2004)

A clinical details form was developed specifically for the CBP to obtain specific information about the services accessed or not accessed. All these forms can be found in Appendix A.

Finally, BIRD's computerised clinical dataset was accessed to obtain demographic and clinical information for each client including the date client was admitted into the BIRP, gender, age, country of birth, main language spoken, indigenous status, age at injury, time since injury, circumstance, duration of PTA and injury severity.

Procedure

Data was collected from BIRP clinicians between February 2007 and December 2008. Forms were completed by 88 clinicians identified to be the clinical informants for the clients included in the study. These clinicians were identified because they had the most complete knowledge of each of the clients.

Clinicians re-rated the OBS three months after the initial data collection if the clinical informant had at least one occasion of service with the relevant client over this same three-month interval. This re-rating was used to establish if there was any change in behaviour over time. If a clinician had not seen a client over the three-month period, they were not required to complete the OBS for the second time because it was assumed they would not have any information on which to re-rate the client.

Identification of challenging behaviour

In order to determine prevalence of challenging behaviour in clients after TBI it was necessary to develop criteria by which challenging behaviour could be recognised and counted. The OBS, the primary challenging behaviour measure in the study, was used to identify clients as challenging or non-challenging. However, it was thought inappropriate to use any of the three summary scores that can be obtained from using the OBS for this purpose because the nature of these indices is to summarise behavioural responses across the nine categories of behaviour assessed. Using these summary scores would have the unwanted effect of excluding clients as cases of challenging behaviour when their challenging behaviour was restricted to only one or a few of the nine areas assessed by the OBS.

Instead, criteria for challenging behaviour were established with reference to the objective (severity level and frequency) and subjective (perceived impact) information available for each of the nine behavioural domains assessed by the OBS. It was decided that any developed criteria should reflect the following three principles:

1. The highest levels of severity of any behaviour should be recognised as challenging regardless of the frequency. This includes unlawful behaviour or behaviour that poses a significant risk of injury or threat to the client or other people.
2. Less severe behaviours or milder forms of problematic behaviour that occur at a sufficient frequency should be considered challenging. This includes disruptive, irritating behaviours that pose a minimal risk of injury or threat to the client or others but occur at sufficient frequency to be burdensome.
3. Regardless of the objective indicators of behaviour, if behaviour is perceived to be challenging, then it would need to be recognised as such. This was considered important because perceptions in and of themselves can have a cascading effect in terms of the supports and services that need to be put in place for the client and family.

In order to operationalise the above principles, the following criteria were used to define challenging behaviour[2]:

Criterion 1:

Any OBS behaviours rated at severity level 3 or 4 were considered challenging regardless of frequency. However, for physical acts against self, physical aggression against other people and/or inappropriate sexual, perseverative and wandering behaviours of severity level 2 were also deemed challenging regardless of frequency.

Criterion 2:

Any OBS behaviours rated at severity level 1 were considered challenging if the frequency of the behaviour was rated to occur at least daily. For verbal aggression, physical aggression against objects and inappropriate social behaviours, severity level 2 was also be considered challenging if the behaviour was rated to occur at least daily. However, for adynamia/lack of initiation, at least many prompts daily were considered challenging.

Criterion 3:

If the perceived impact of any of the nine behaviours on the OBS was rated as severe or extreme, then they were considered challenging.

Table 1 illustrates the type of behaviours that were defined as challenging on the basis of the first two criteria.

Table 1: OBS cut-off criteria for challenging behaviour

	Challenging behaviour at any frequency	Challenging behaviour when occurring daily or more
Verbal aggression	4 Makes clear threats of violence toward others or self, requests help to control self	2 Makes mild personal insults but no swearing
	3 Swearing, moderate threats directed at others or self	1 Makes loud noise, shouts angrily
Physical aggression against Objects	4 Sets fire, throws object dangerously	2 Throws object down, kicks furniture without breaking
	3 Breaks objects, smashes windows	1 Slams door, scatters clothing, makes mess

[2] Because on the OBS Adynamia/lack of initiation behaviour is only rated in terms of frequency and perceived impact but not severity level, it could only be considered using criteria 2 and 3. If adynamia/lack of initiation occurred daily (criterion 2) then it was considered challenging or if adynamia/lack of initiation had a severe or extreme perceived impact (criterion 3) then is was considered challenging.

Table 1 (continued): OBS cut-off criteria for challenging behaviour

	Challenging behaviour at any frequency	Challenging behaviour when occurring daily or more
Physical acts against Self	4 Mutilates self, causes deep cuts, fracture. Includes suicide attempt	1 Picks or scratches skin, hits self, pulls hair
	3 Inflicts small cuts/bruises	
	2 Bangs head, hits fist into objects, throws self on floor (hurts self but not serious injury)	
Physical aggression against Others	4 Causes severe physical injury (fracture, cut)	1 Threatening gesture, swings at people, grabs clothes
	3 Causes mild-moderate injury (bruise)	
	2 Strikes, kicks, pushes, pulls hair	
Inappropriate sexual behaviour	4 Attempt to forcibly undress another person, threat to obtain sex, rape	1 Touching other people who don't want to be touched, kissing hand, patting knee
	3 Attempt or act of touching other people's genitals	1 Comments of a sexual nature
	2 Masturbation in public	
	2 Exhibitionism in public	
Perseveration/Repetitive behaviour	3 Engages in prolonged repetition resulting in serious physical harm	1 Engages in prolonged repetition that does not result in physical harm
	2 Engages in prolonged repetition resulted in minor physical harm	
Wandering/ Absconding	3 Escapes secure premises and may resist attempts to stop escape	1 Going into areas that are prohibited but where there is no or low risk of harm
	2 Leaves a safe place when there is risk of becoming lost or of harm	
Inappropriate social behaviour	4 Presents a danger to self or others, lights fires dangerously, crosses road recklessly	2 Nuisance/ annoyance, interrupts conversations, actively seeks attention
	4 Petty crime or unlawful behaviour, driving unlicensed, stealing cigarettes	1 Socially awkward, inappropriate laughter, failure to monitor personal hygiene, standing too close
	3 Non-compliant or oppositional	
Adynamia/ Lack of initiation[3]		Person requires many prompts daily to undertake activities of daily living

[3] Adynamia/lack of initiation is not rated in terms of severity on the OBS. It is only rated in terms of frequency. In the Challenging Behaviours Project adynamia was defined as challenging when prompting was required many time per day.

Quantitative data analysis

Non-parametric statistical tests were used to analyse the data collected. Specifically:

- Chi-squared test – to analyse the relationship between two categorical or ordinal variables[4]
- Mann-Whitney U test – to analyse the differences between two groups against a dependent continuous variable
- Kruskal-Wallis test – to analyse the differences between more than two groups against a dependent continuous variable
- Multinomial binary logistic regression – to test the ability of multiple variables to predict membership of two groups (challenging versus non-challenging behaviour)

The probability for a Type-I error of less than 5% was required for statistic relationships to be considered significant (i.e. $p<0.05$).

Qualitative case review

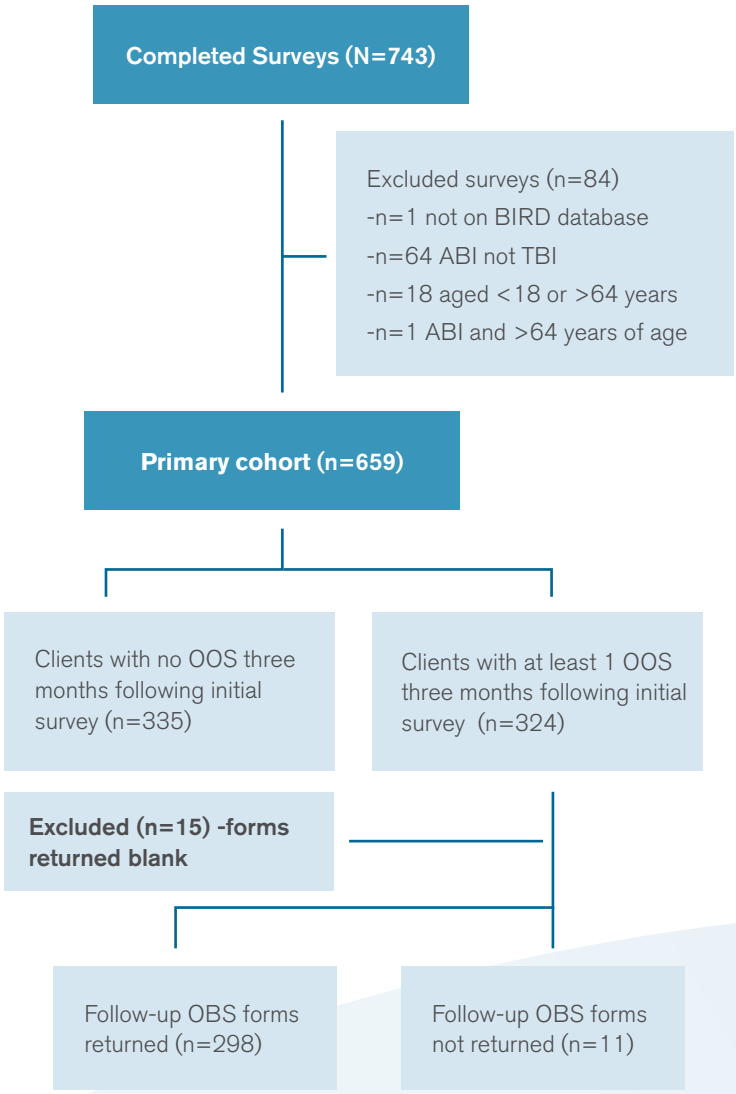
Another stage of the CBP was to have each of the 11 BIRP services identify up to four clients considered particularly challenging in terms of behaviour for qualitative review. It was expected that a thorough review of this select group of clients may provide additional information about challenging behaviours that could not be provided by analysis of the quantitative data alone.

A semi-structured interview (see interview questions in Appendix B) was undertaken with a clinician who knew the clients' challenging behaviours, treatments received and background well. Whenever convenient, sometimes before and sometimes after interview, the medical record and case notes of the clients included for qualitative review were examined to obtain background and injury details and also to gain further understanding of any behavioural issues.

The information collected from each client was then written up into a case history by either JMR or MS. In the interest of privacy these case studies have been withheld.

Each of the case histories was then read to identify themes relating to the challenging behaviours of clients who sustain TBI.

Figure 2: Flow-chart of clients included in study.



RESULTS

To determine the prevalence, co-morbidities and burden of challenging behaviours, a total of 743 BIRP clients were rated by clinician informants. However, after extraction of data from the ACI: BIRD computerised database, it was discovered that 84 clients did not meet criteria for inclusion in the study (see Figure 2). Therefore, the final client sample comprised 659 individuals.

To establish the course of challenging behaviours, clients were reassessed three months after their initial assessment. To be included in this second assessment, clients needed to have had at least one occasion of service during the three-month interval. A study flow chart is displayed in Figure 2. A summary of the demographic and clinical characteristics of the 659 clients in the study can be viewed in Appendix C.

PREVALENCE OF CHALLENGING BEHAVIOURS

The prevalence of challenging behaviour was 53.1%, representing 350 community TBI clients across the NSW BIRP network who met criteria for challenging behaviour (see Table 1).

Prevalence of different types of challenging behaviour

Aggression (including verbal and physical forms) was the most common type of challenging behaviour,shown by 31.1% of clients. Table 2 shows the prevalence of the nine different types of challenging behaviours assessed by the OBS. The three most common challenging behaviours were inappropriate social behaviour, verbal aggression and adynamia/lack of initiation.

[4] Fisher Exact tests were used when the categorical/ordinal variables had no more than two levels.

Table 2: Prevalence of the nine types of challenging behaviour

	N	%
Inappropriate social behaviour	200	30.3
Verbal aggression	173	26.3
Adynamia/Lack of initiation	149	22.6
Perseveration/repetitive behaviour	84	12.7
Physical aggression against others	69	10.5
Physical aggression against objects	49	7.4
Physical acts against self	32	4.9
Inappropriate sexual behaviour	23	3.5
Absconding/Wandering	19	2.9

Table 3: Challenging behaviour by gender

	Males n (%)	Females n (%)
Verbal aggression*	143 (28.4)	30 (19.2)
Physical aggression against objects*	47 (9.3)	2 (1.3)
Physical acts against self	23 (4.6)	9 (5.8)
Physical aggression against others	57 (11.3)	12 (7.7)
Inappropriate sexual behaviour	20 (4.0)	3 (1.9)
Perseveration/repetitive behaviour	68 (13.5)	16 (10.3)
Absconding/wandering*	19 (3.8)	0 (0.0)
Inappropriate social behaviour*	165 (32.8)	35 (22.4)
Adynamia/lack of initiation	120 (23.9)	29 (18.6)

Note: *p<0.05

FACTORS RELATED TO PREVALENCE

Having established the prevalence of challenging behaviours, a series of analyses was then undertaken to examine whether demographic and clinical variables including sex, age, country of birth, preferred language, indigenous status, geographic location, age at injury, circumstances of injury, duration of PTA, disability level and the presence of cognitive problems influenced the presence of challenging behaviours.

Gender

A higher proportion of males (55.3%) than females (46.2%) demonstrated challenging behaviour. This difference was marginally significant (p=0.05). Examining specific types of challenging behaviour, males had significantly higher rates of verbal aggression, physical aggression against objects, absconding/wandering and inappropriate social behaviour compared with females (p<0.05). No other comparisons were significant (see Table 3).

Table 4: Challenging behaviour by PTA duration

	<24 hours (n=26)	2-6 days (n=71)	1-4 weeks (n=170)	1-6 months (n=232)	>6 months (n=42)
All behaviours	30.8	38.0	44.7	57.8	76.2
VA*	19.2	12.7	21.8	28.9	45.2
PAO	11.5	5.6	7.1	8.6	4.8
PAS	3.8	4.2	7.6	2.2	4.8
PAP*	7.7	4.2	7.6	11.6	26.2
ISB*	3.8	1.4	1.8	2.6	16.7
PR*	3.8	4.2	6.5	16.9	33.3
WA	0.0	2.8	2.9	3.0	4.8
ISOC*	0.0	14.1	26.5	37.9	47.6
ADL*	3.8	19.7	11.2	25.9	42.9

Note. *p<0.05. VA=Verbal aggressive behaviour; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseveration/ repetitive behaviour; WA=Wandering/absconding; ISOC=Inappropriate social behaviour; ADL=Adynamia/lack of initiation.

Age

Age was not significantly related to absence or presence of any of the different types of challenging behaviour (p>0.05). The median age was 37.2 years for clients with challenging behaviour and 38.3 years for clients without challenging behaviour.

Country of birth and preferred language

There was no significant relationship between challenging behaviour and country of birth (Australia versus overseas) (p>0.05). However, there was a trend toward clients whose preferred language was English to have more challenging behaviour (54.1%) compared to those who preferred to speak another language (40.7%) (p=0.05). Neither country of birth nor language was significantly related to individual types of challenging behaviour.

Indigenous status

22 study participants (3.4%) were identified as indigenous. There was a trend for indigenous clients to have more challenging behaviour (72.7%) compared to non-indigenous clients (53.2%) (p=0.08). This was also reflected in the higher rate of wandering/absconding amongst indigenous clients (13.5%) compared with non-indigenous clients (2.5%) (p<0.05).

Geographic location

Clients resident in remote areas demonstrated the highest rate of challenging behaviour (61.4%) followed by regional (59.8%) and then urban clients (49.6%). This difference in the rate of challenging behaviour for different geographical locations was statistically significant (p<0.05). At the level of individual behaviours, none was significantly related to geographical location.

Table 5: Challenging behaviour by level of disability

	n	%
No disability	19	23.2
Mild disability	35	29.2
Partial disability	97	50.8
Moderate disability	136	73.1
Moderate to severe disability	50	87.7
Severe disability	6	100.0
Extremely severe disability	4	40.0

The relationship between level of disability and different types of challenging behaviours is displayed in Figure 4.

Age at injury

Clients with and without challenging behaviour were at equivalent ages when they sustained their injuries ($p>0.05$). However, clients with two specific forms of challenging behaviour were younger at the time of sustaining their injuries compared with clients without these challenging behaviours:

- Physical aggression against objects:
  Clients displaying this behaviour had a median age at injury of 35.3 years compared with 38.3 years for clients without this behaviour ($p<0.05$).
- Physical aggression against others:
  Clients displaying this behaviour had a median age at injury of 25.5 years compared with 31.1 years for clients without this behaviour ($p<0.05$).

Although the clients displaying these two challenging behaviours were significantly younger, in a statistical sense, the age difference was not considered clinically meaningful.

Injury circumstances

Injury circumstance (MVA/MBA related, assault, fall, sport/leisure or other TBI) was not related to the absence or presence of challenging behaviour overall nor was it significantly related to any specific type of challenging behaviour.

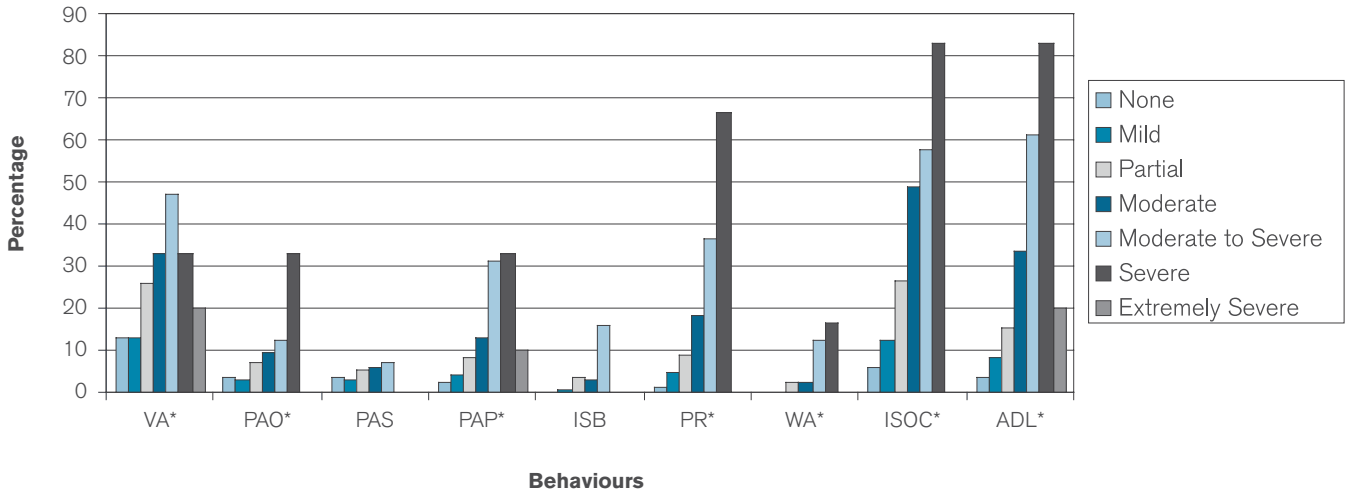
Post-traumatic amnesia

Overall, the rate of challenging behaviours increased significantly with increasing duration of PTA (see Table 4). This increase was statistically significant ($p<0.05$).

Disability

The rate of challenging behaviour increased from 23% for those with no disability to 100% for clients with severe disability. However, for those with extremely severe disability there was a decline in challenging behaviour compared with those with severe disability, but their rate of challenging behaviour was still elevated compared to no and mild disability clients. This can be seen in Table 5.

Figure 3: Challenging behaviour types by level of disability.



VA=Verbal aggression; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseveration/repetitive behaviour; WA=Wandering/absconding behaviour; ISOC= Inappropriate social behaviour; ADL=Adynamia/lack of initiation

Five points can be made by examining Figure 3:

1. Challenging behaviours increase as disability increases from mild to severe disability and this increase is statistically significant for all behaviours except physical aggression against self.

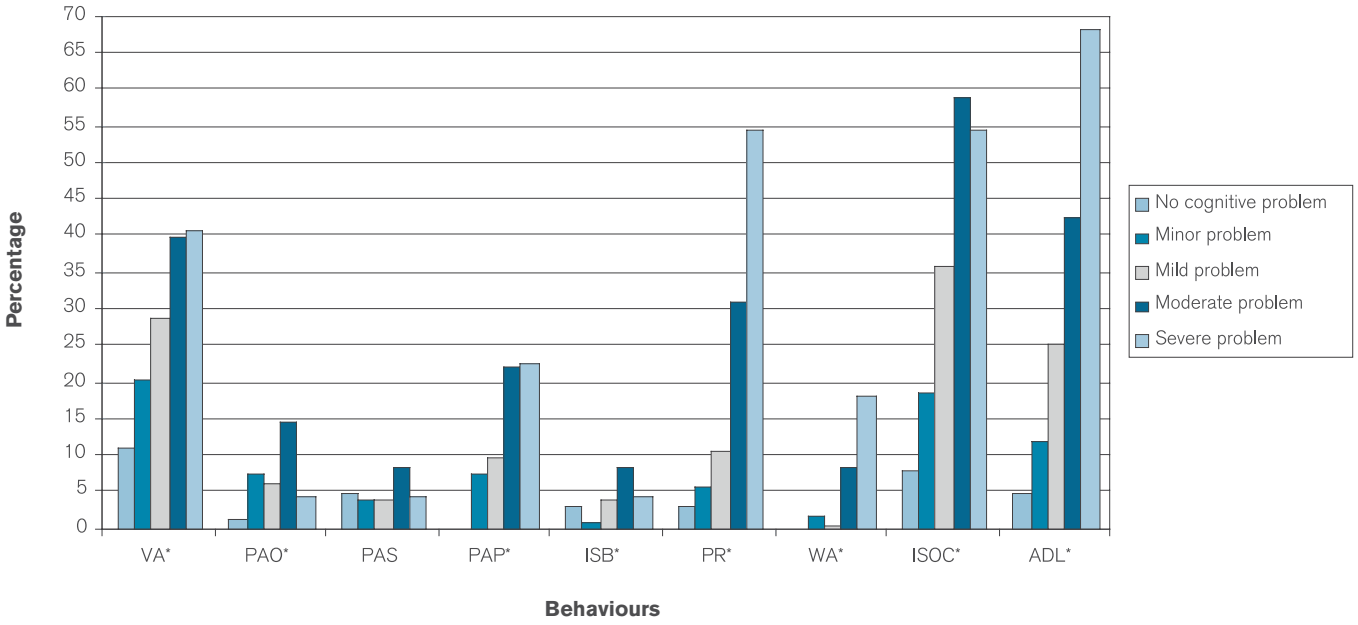
2. There is generally a lower rate of challenging behaviour for those with extremely severe disability.

3. Clients with extremely severe disability only have three types of behaviour at a level that would be considered challenging (verbal aggression, physical aggression against other people and adynamia/lack of initiation) .

4. No clients with severe disability displayed physical aggression against self or inappropriate sexual behaviour at a challenging level.

5. Some level of disability was required before inappropriate sexual behaviour and wandering/absconding met criteria as challenging.

Figure 4: Challenging behaviour types by level of cognitive problem.



VA=Verbal aggression; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseveration/repetitive behaviour; WA=Wandering/absconding behaviour; ISOC=Inappropriate social behaviour; ADL=Adynamia/lack of initiation

Cognitive problems

Rates of challenging behaviours increased as severity of cognitive impairment increased. The rate of challenging behaviour for each level of cognitive impairment was:

- 21% (n=13) of clients with no cognitive problems
- 39.8% (n=96) of clients with minor cognitive problems
- 61.7% (n=132) of clients with mild cognitive problems
- 79.6% (n=82) of clients with moderate problems, and
- 90.9% (n=20) of clients with severe cognitive problems

This increasing rate of challenging behaviour with increasing cognitive impairment was statistically significant ($p<0.05$).

There was a significant association between severity of cognitive problems and all types of challenging behaviour except for physical aggression against self. These relationships are depicted in Figure 4. The key findings are that:

- There was a steady increase in the rate of perseveration and adynamia/lack of initiation as cognitive problems increased
- There was a plateau in the rate of verbal aggression, physical aggression against other people and inappropriate social behaviour once the cognitive problems reached the moderate level
- Physical aggression against objects and inappropriate sexual behaviour did not increase in a consistent fashion in relation to severity of cognitive problems.

Accommodation problems

Generally, rates of challenging behaviours increased as severity of accommodation problems increased:

- 43.3% (n=195) of clients with no accommodation problems
- 71.9% (n=97) of clients with minor accommodation problems
- 65.9% (n=29) of clients with mild accommodation problems
- 97.4% (n=17) of clients with moderate accommodation problems, and
- 100.0% (n=12) of clients with severe accommodation problems

This generally increasing rate of challenging behaviour with increasing accommodation problems was statistically significant ($p<0.05$). The relationship between specific challenging behaviours and accommodation problems was examined by undertaking Pearson's chi-squared. However, the expected cell frequencies were low in a number of cross-tabulations and therefore, the resulting chi-square relationships were not necessarily reliable and so are not presented here. The results of these analyses are presented in Appendix D.

COURSE OF CHALLENGING BEHAVIOURS

The course of challenging behaviour was determined by following up a subset of clients three months after the initial behavioural survey. Only clients who had at least one occasion of service with their clinical informant during the three-month follow-up interval were included.

Three hundred and twenty-four clients met this criterion and their clinical informants were sent the OBS for re-rating, with 313 surveys returned (96.6% response rate). However, 15 of the returned OBS forms had no responses endorsed and, therefore, were not included in the follow-up analysis. Six of the 15 blank response forms were for clients who met criteria for challenging behaviour on the initial survey. Therefore, valid data was available for 298 clients to examine the course of challenging behaviour – see Figure 2.

The prevalence of challenging behaviour at three-month follow-up was 52.4%, which was not significantly different to the prevalence of 53.1% reported at the time of initial survey using the entire sample.

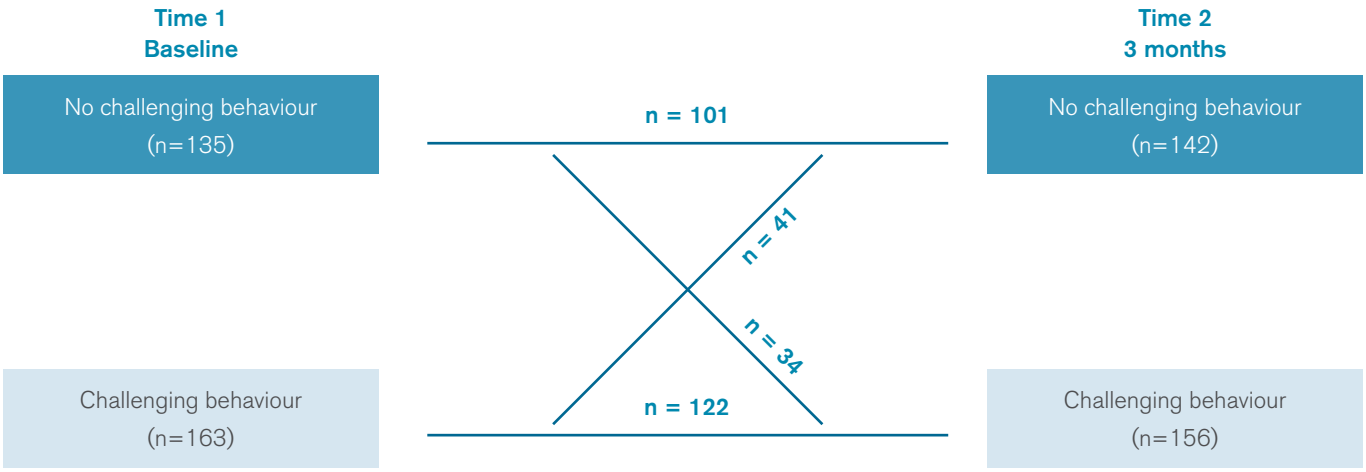
As can be seen in Figure 5, of the 298 clients with valid follow-up OBS data, 223 (74.8%) did not change their behavioural classification:

- 33.9% (n=101) clients without challenging behaviours on initial survey remained non-challenging at three months
- 40.9% (n=122) who were challenging at baseline remained challenging at three-months

As can be seen in Figure 5, of the 75 clients who changed their behavioural classification over the three-month follow-up:

- 11.4% (n=34) developed challenging behaviour over the three-month period
- 13.8% (n=41) were challenging at baseline but improved and were not challenging at the three-month assessment.

Figure 5: Course of challenging behaviour over three-month follow-up.



CO-MORBIDITY AND CHALLENGING BEHAVIOURS

The next aspect of investigation was to look at the relationship between co-morbidity (mental health and drug and alcohol problems) and challenging behaviours. Mental health problems included depressive symptoms, self-directed injuries, psychotic features/confabulation and 'other mental problems' as defined by the HoNOS-ABI.

Current mental health co-morbidity

The rates of challenging behaviour for different levels of mental health problems covered by the HoNOS-ABI are displayed in Figure 6.

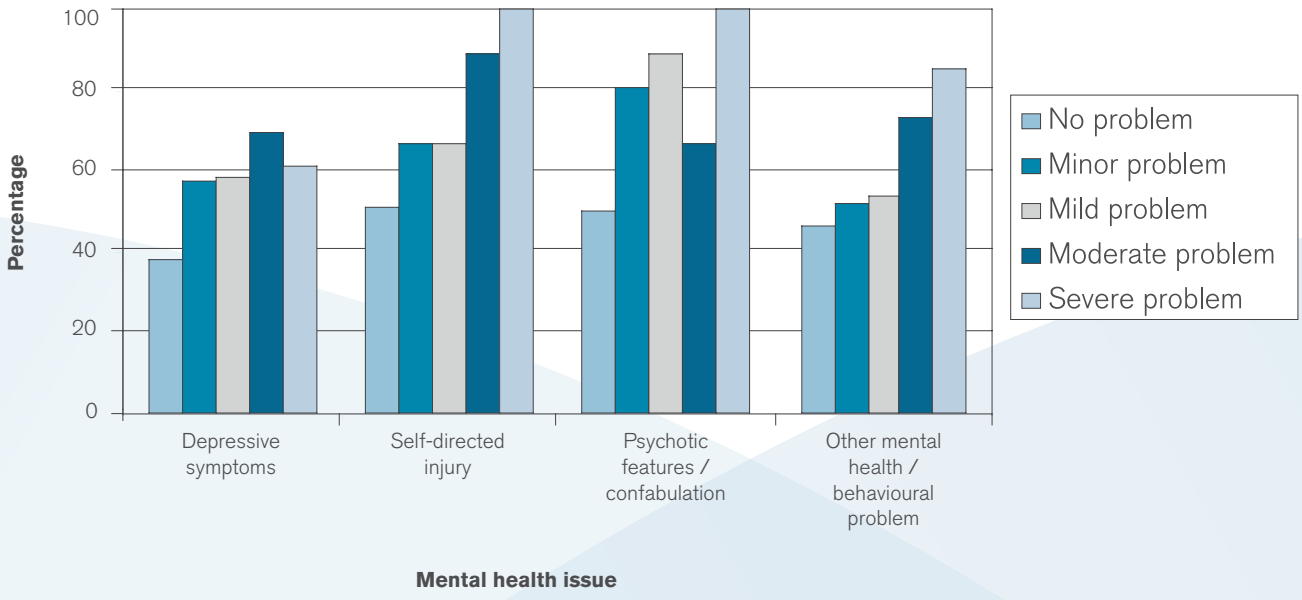
Challenging behaviour was significantly related ($p<0.05$) to:

- Depressive symptoms
- Self-directed injury
- Psychotic features/confabulation
- Other mental problems

These relationships revealed that clients with any level of depressive symptoms had higher rates of challenging behaviour. There was a general trend for an increase in the rate of challenging behaviour as the intensity of self-directed injury, psychotic features/confabulation and other mental problems increased. It is noteworthy that all clients with severe self-directed injury and psychotic features/confabulation had challenging behaviour.

The relationship between specific challenging behaviours and mental health problems was examined by undertaking Pearson's chi-squared. However, the expected cell frequencies were low in a number of cross-tabulations involving different mental health issues and particular challenging behaviours and, therefore, the resulting chi-square relationships were not necessarily reliable and so were not presented here. The results of these analyses are presented in Appendix D.

Figure 6: Challenging behaviour by mental health issues.



Moderate and severe mental health problems reflect clinical indicators such as frequent/persistent thoughts or talking about self-harm, suicide attempts, subjective/objective measures of marked depression, distress, hallucinations, delusions and bizarre behaviour.

Current drug and alcohol co-morbidity

The HoNOS-ABI drug and alcohol item was used as an indicator of current levels of drug and alcohol co-morbidity. Overall, as drug and alcohol problems became more severe there was a corresponding significant increase in the proportions of clients also displaying challenging behaviour ($p<0.05$). The rates of challenging behaviour for different levels of problem with drugs and alcohol were:

- No co-morbidity 45.8% (205)
- Minor problem 54.3% (38)
- Mild problem 75.0% (39)
- Moderate problem 80.4% (37)
- Severe problem 92.3% (24)

Significantly higher rates of verbal aggression ($p<0.05$), physical aggression against objects ($p<0.05$), physical aggression against others ($p<0.05$), wandering/absconding ($p<0.05$) and inappropriate social behaviour ($p<0.05$) were also apparent as severty of drug and alcohol co-morbidity increased.

Pre-morbid alcohol and psychiatric history

The possible contribution of a pre-morbid history of alcohol abuse or psychiatric disturbance to post-injury challenging behaviours was also investigated.

A total of 73.2% of clients with a pre-injury history of significant alcohol abuse displayed post-injury challenging behaviours, compared to 46.5% without such a history ($p<0.05$). The rate for different types of challenging behaviour was also associated with client's pre-morbid history of alcohol abuse (see Figure 5).

Similarly, a total of 72.0% of clients with a pre-injury history of significant psychiatric disturbance had post-injury challenging behaviour, compared with 50.0% of clients without such a history ($p<0.05$). The rate for different types of challenging behaviour was also associated with clients' pre-morbid history of psychiatric disturbance (see Figure 8).

Figure 7: Challenging behaviour types by pre-morbid alcohol abuse.

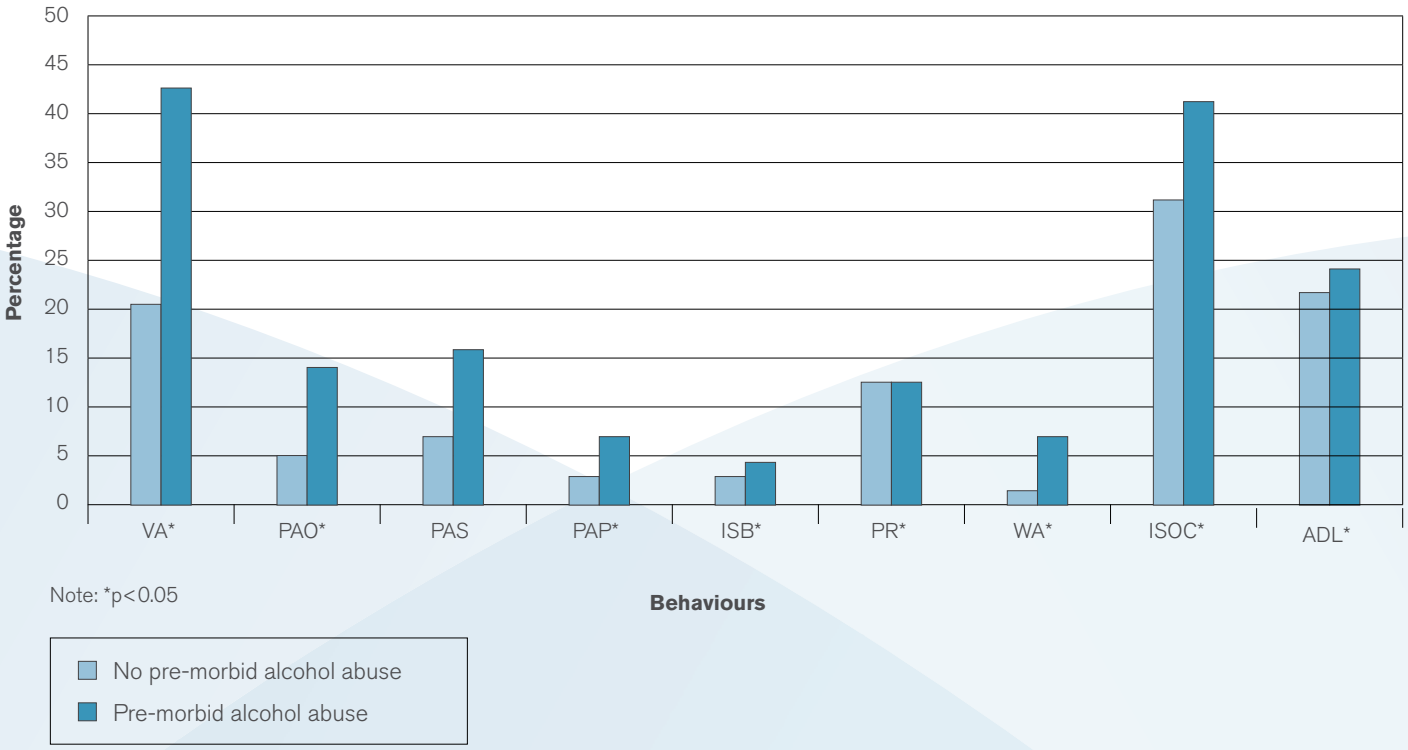


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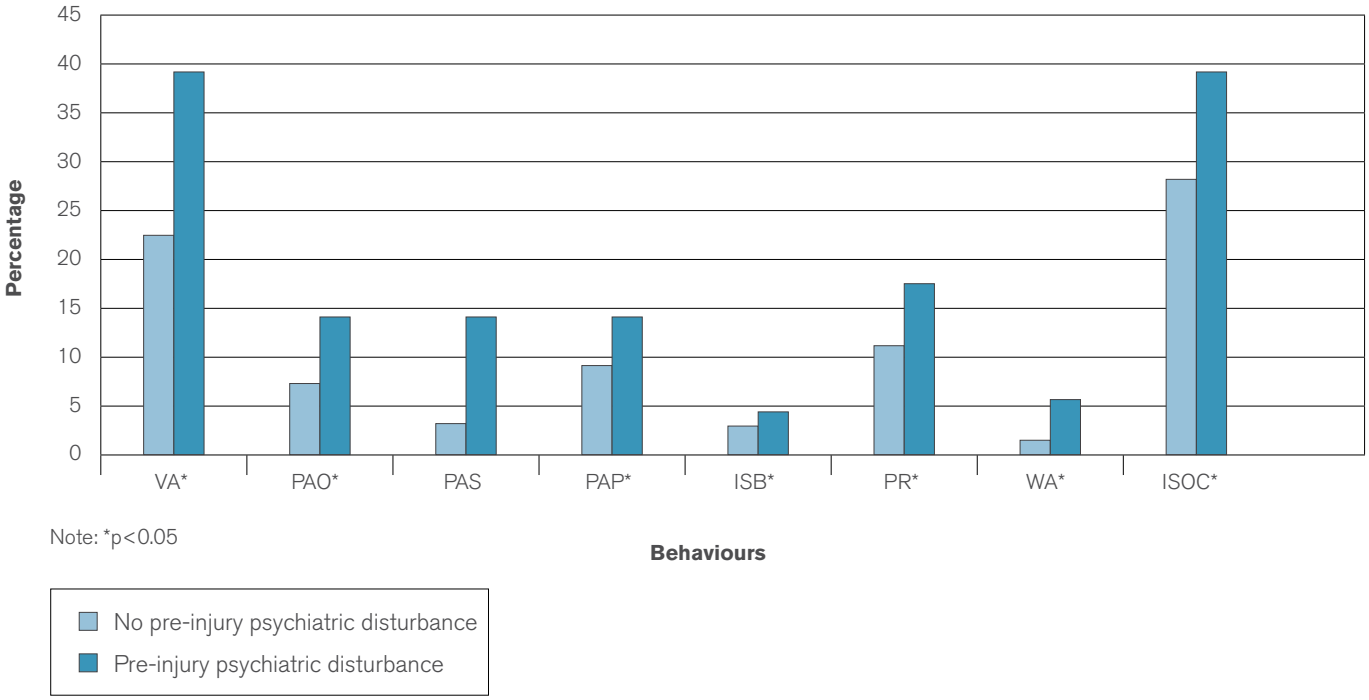
Figure 8: Challenging behaviour types by pre-injury psychiatric disturbance.



Note: *p<0.05

VA=Verbal aggression; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseveration/repetitive behaviour; WA=Wandering/absconding behaviour; ISOC=Inappropriate social behaviour; ADL=Adynamia/lack of initiation

Importance of co-morbid conditions for challenging clients

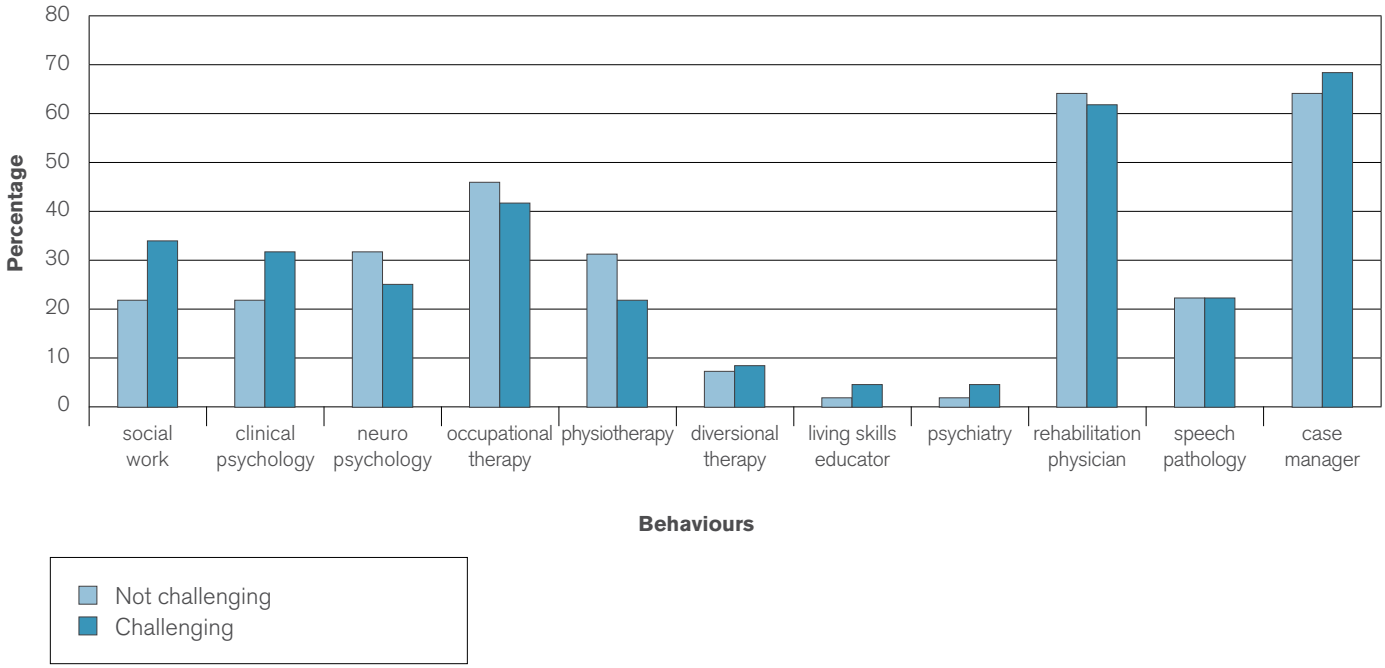
Although clients with co-morbid mental health and drug and alcohol problems were more likely to have challenging behaviour, challenging behaviour is also associated with a variety of other demographic and clinical variables, as shown on pages 12-16. Therefore, co-morbid problems were examined to determine whether they made a unique contribution to the presence (versus absence) of challenging behaviours when other variables were also considered.

This proposition was tested using a binary logistic regression analysis with forward stepwise selection criteria. The results of the analysis demonstrated that six variables independently predicted the presence of challenging behaviour (p<0.05):

1. Pre-injury alcohol problem
2. Current drug and alcohol problem
3. Other mental health problems
4. Level of disability
5. Cognitive problems
6. Depressive symptoms

The remaining variables did not significantly contribute further in explaining the presence versus absence of challenging behaviour (p>0.05). The above six factors together were able to correctly classify 74.2% of clients as having or not having challenging behaviour, with a sensitivity of 76.3% and specificity of 71.8%. The statistical parameters of this model can be found in Appendix E.

Figure 9: Challenging behaviour by BIRP services.



BURDEN OF CHALLENGING BEHAVIOUR

Participation of clients with challenging behaviour

The first question to be investigated was whether challenging behaviour acted as a significant predictor of participation. Three levels of participation were documented: good; poor; and between the two, limited participation. Level of participation was determined using the SPRS.

There was a significant relationship between client participation and challenging behaviour ($p<0.05$). Whilst only 5% of clients with challenging behaviour had good levels of participation, 54% and 49% of clients with challenging behaviour had limited and poor levels of participation respectively. In contrast, 30% of clients without challenging behaviour had good levels of participation, 60% had limited participation and only 10% of non-challenging clients had poor participation.

Care needs of clients with challenging behaviour

It is well known that a number of factors contribute to people's care needs but it has not been established if challenging behaviour independently contributes. The CANS was used to establish each client's level of care and support needs. Three levels of care and support needs are derived from the CANS: no care needs; intermediate (less than daily) care needs; and high (daily) care needs.

There was a significant relationship between client care and support needs and challenging behaviour ($p<0.05$). Only 11% of clients with challenging behaviour had no care and support needs, whereas 43% and 46% needed intermediate and high levels of care and support respectively. In contrast, only 19% of non-challenging behaviour clients need high level care and support need whereas 53% required intermediate and 29% required no level of care and support.

BIRP service delivery to clients with challenging behaviour

The burden placed on BIRP to provide services to clients with challenging behaviour was evaluated in several ways including consideration of the type and number of staff required; the specific services provided; the stress experienced by clinicians working with clients; and staff perception of client complexity.

BIRP staff providing services to clients

There was no significant difference in the number of BIRP staff managing clients with and without challenging behaviour ($p>0.05$). However, clients with challenging behaviour were significantly more likely to be seen by particular BIRP professionals ($p<0.05$; see Figure 9). In particular:

- 35.4% were seen by a BIRP social worker compared with 23.3% of clients without challenging behaviour
- 34.3% were seen by a BIRP clinical psychologist compared with 25.6% of clients without challenging behaviour

In contrast to psychologists and social workers, physiotherapists were significantly more likely to see clients without challenging behaviour. Other professional groups were no more likely to see clients with or without challenging behaviour.

There were significantly fewer BIRP staff managing clients in remote and regional areas compared to urban locations ($p<0.05$). Whilst a median of three BIRP staff provided services to urban clients, regional and remote clients received services from a median of two BIRP staff.

Figure 10 shows that challenging behaviour clients located in regional and/or remote areas were significantly less likely to receive services from five BIRP professions ($p<0.05$), and challenging behaviour clients in remote regions of the state were significantly more likely to receive case management services than urban and regional clients ($p<0.05$).

Together these findings indicate that geographically isolated clients were more likely to be offered a generic case management service by BIRP rather than specific therapy and medical services.

Services provided by clinical informants to clients

Clients with challenging behaviours received significantly more services from the BIRP clinical informants compared to clients without challenging behaviour ($p<0.05$; see Figure 11).

Figure 10: BIRP staff by client geographic location.

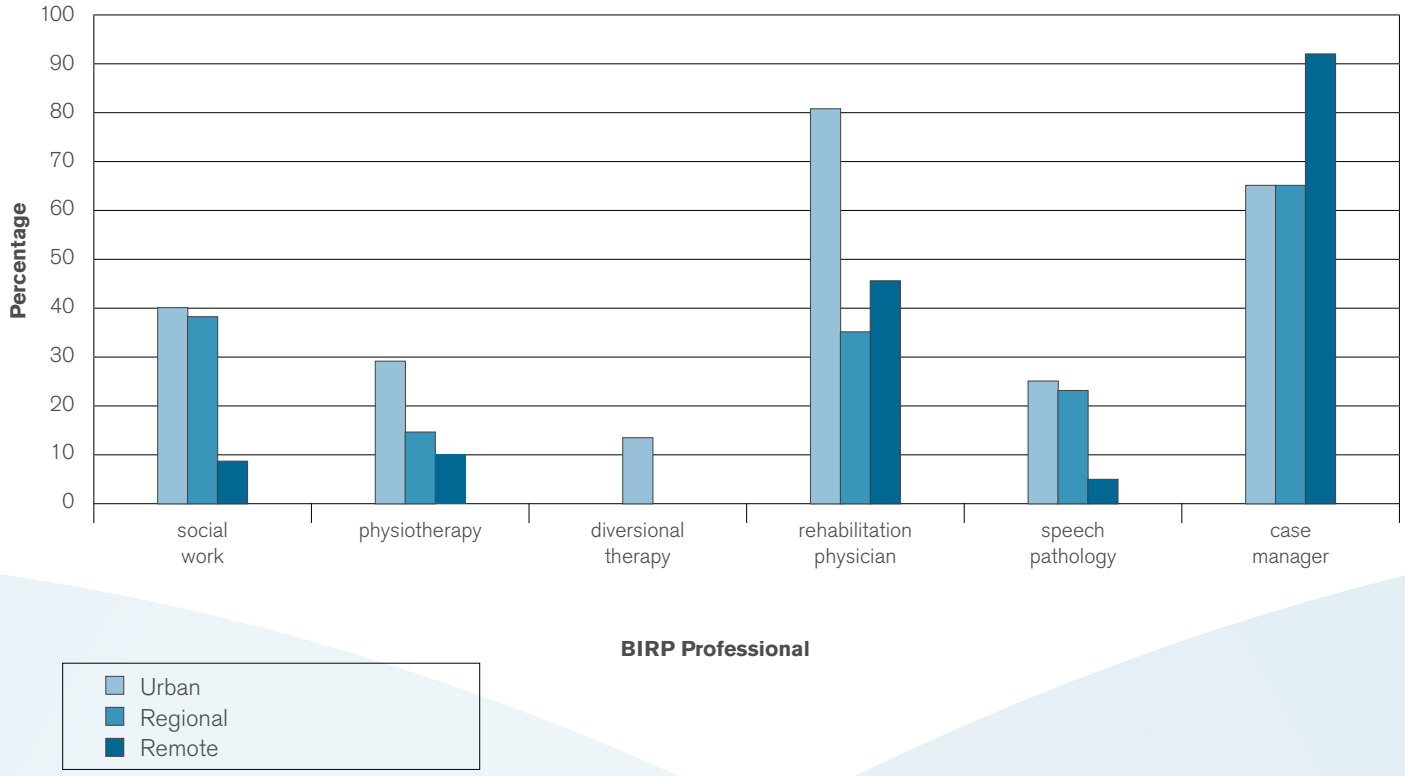
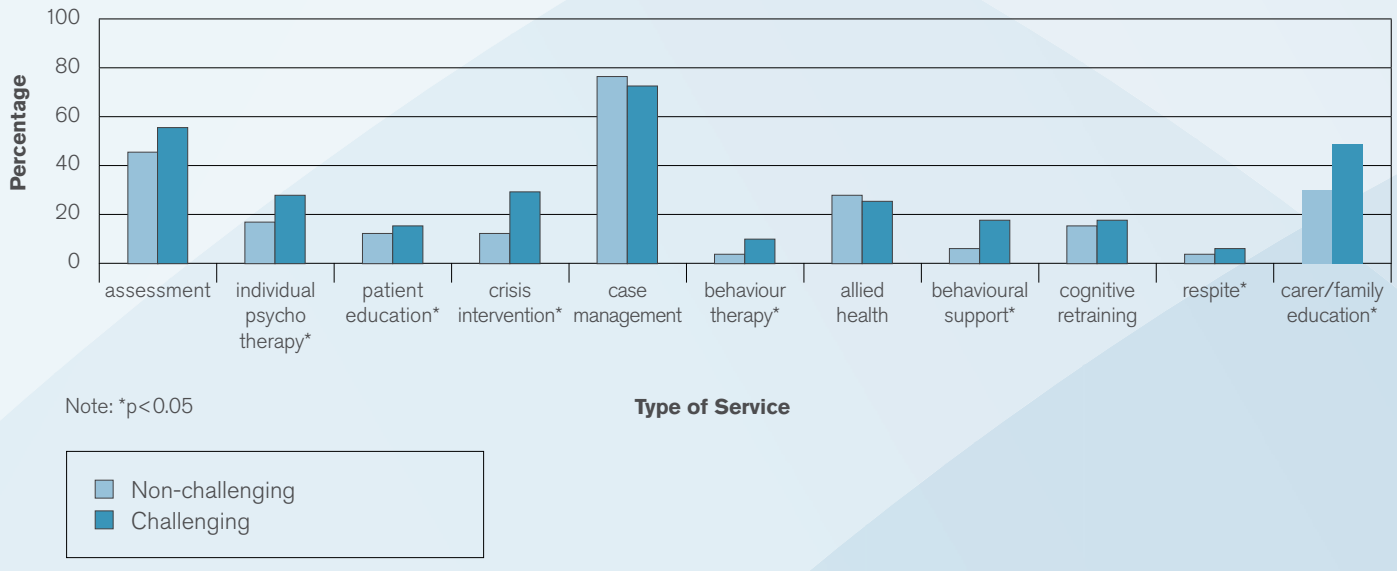
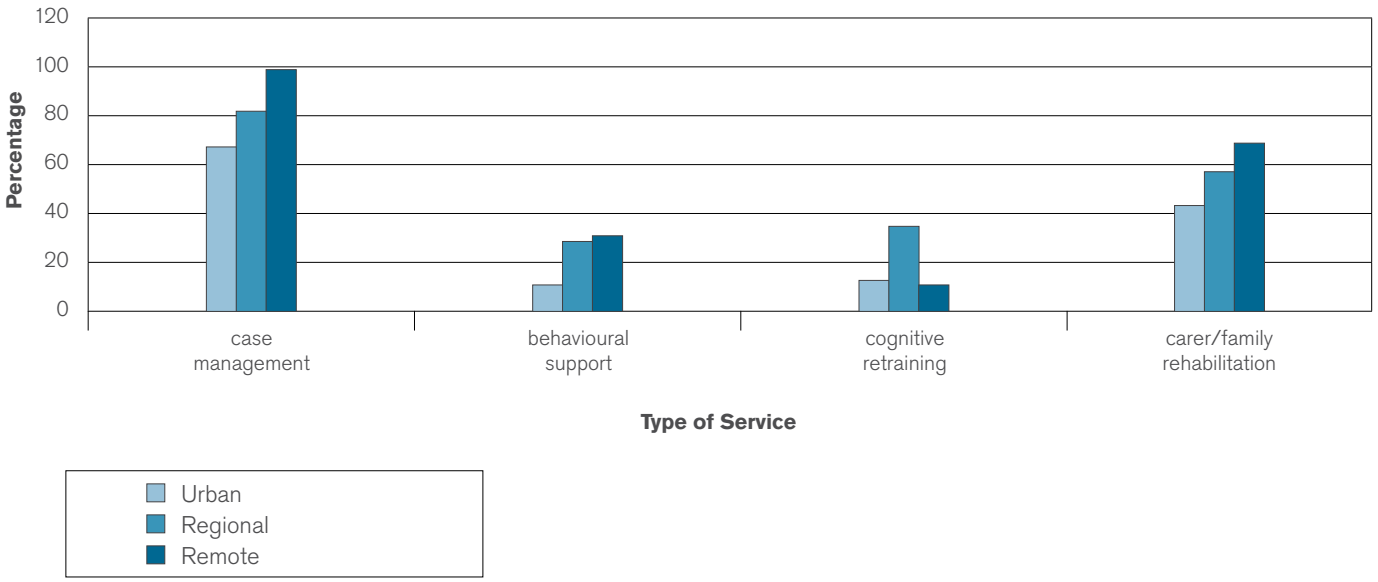


Figure 11: Challenging behaviour by clinical informant services.



Note: *$p<0.05$

Figure 12: Clinical informant service by challenging behaviour client location.



Clinical informants provided clients with challenging behaviours significantly more services compared with clients without challenging behaviour, including individual psychotherapy or counselling, psycho-education, crisis intervention, behaviour therapy, behavioural support, respite and education/training for carer/family.

Clinical informants provided assessment, case management and allied health (occupational, physical or speech therapy) to an equivalent number of challenging and non-challenging clients.

The geographical location of clients influenced the number of services provided to them by clinical informants, who provided significantly more services to clients in remote, then regional areas compared with urban clients ($p<0.05$). Whilst urban clients had a median of two services provided to them, both regional and remote clients had a median of three services provided.

Figure 12 shows that challenging behaviour clients located in regional and/or remote areas were significantly more likely to receive four types of services from clinical informants ($p<0.05$).

Together the results indicate that whilst challenging behaviour clients who were geographically isolated had difficulty accessing BIRP services generally, the clinical informants in the current study attempted to make up for this shortfall in servicing, by providing available services more frequently.

Figure 13: Challenging behaviour and clinician stress

Figure 14: Challenging behaviour and client complexity.

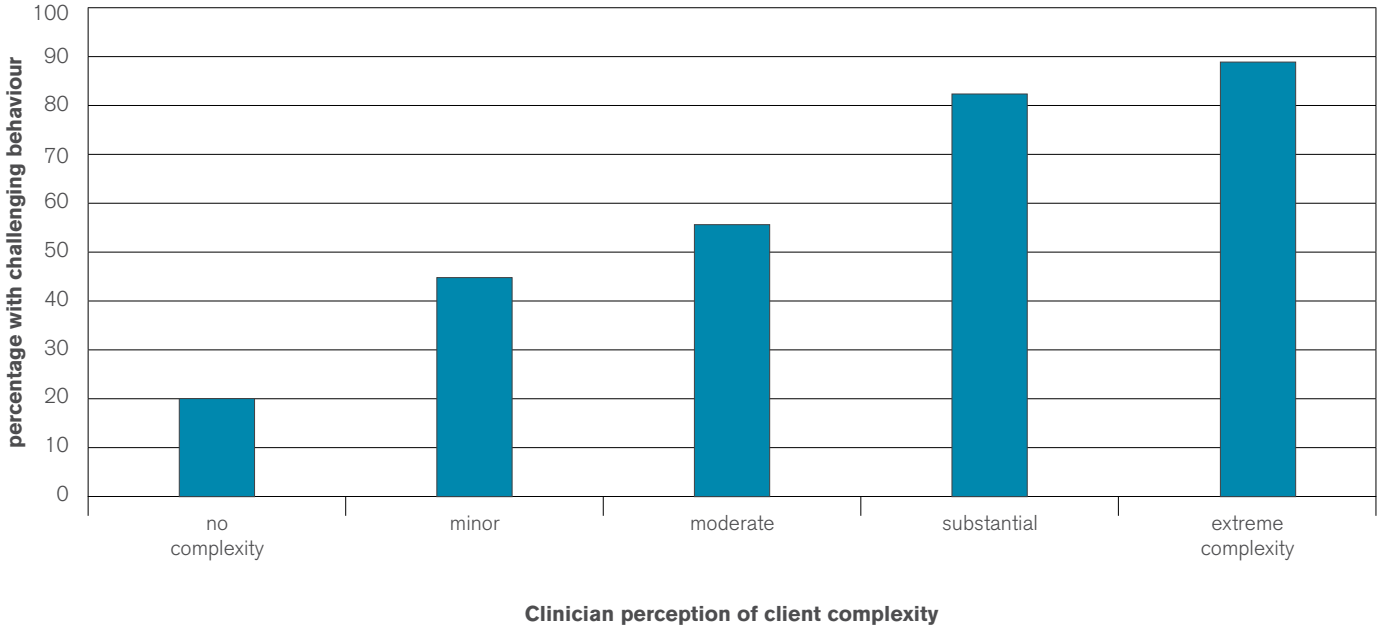


Figure 15: Client complexity by client geographic location.

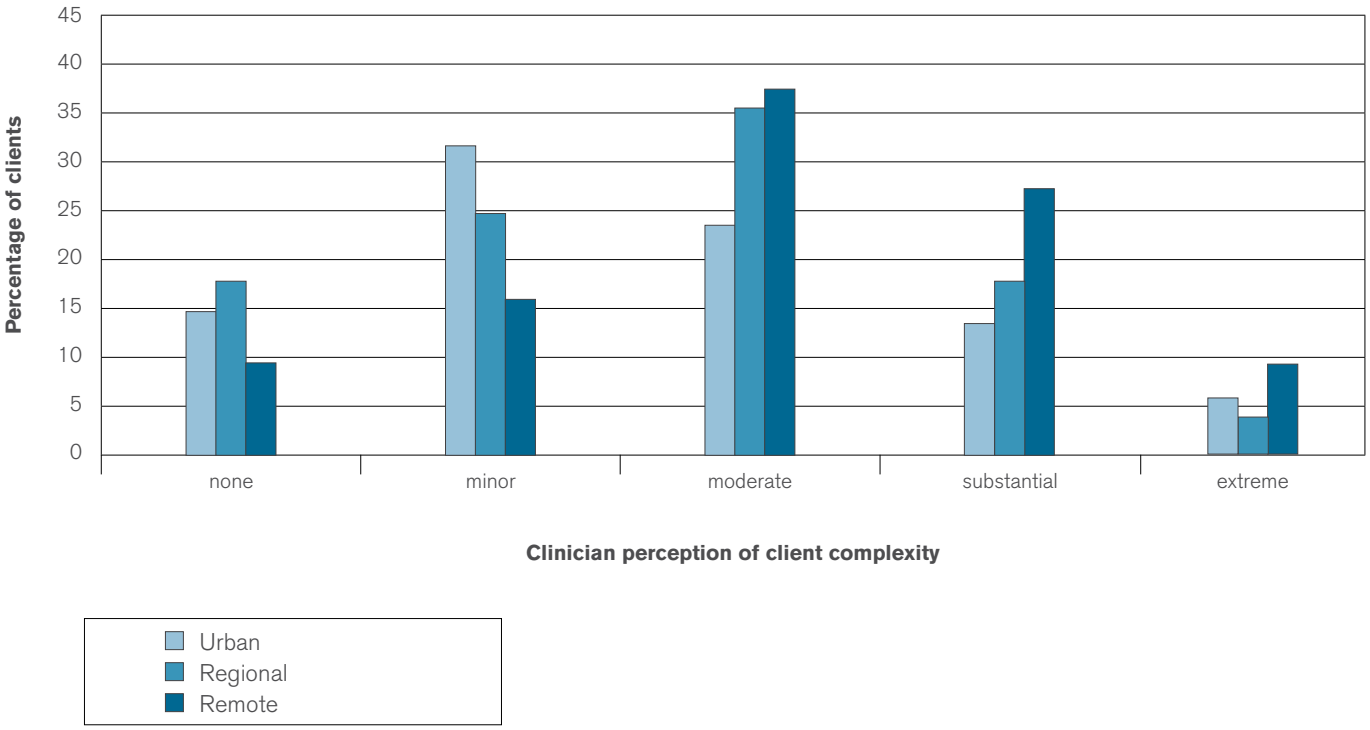
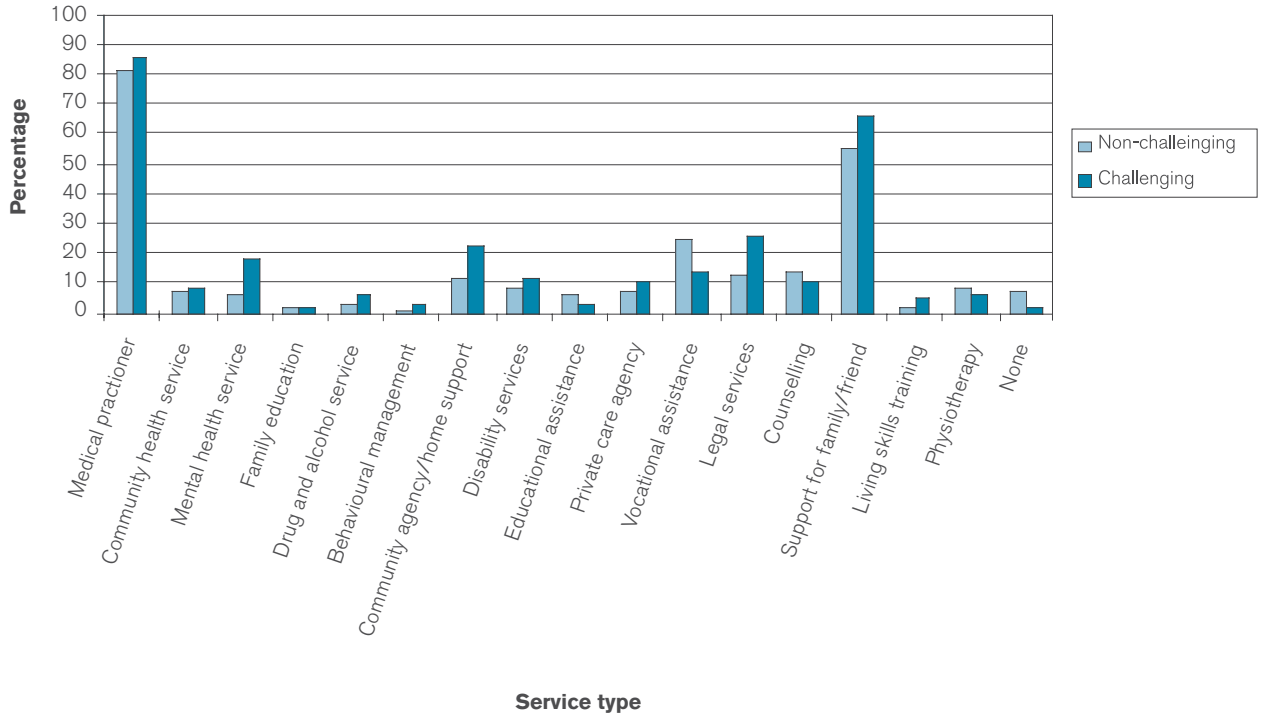


Figure 16: Challenging behaviour by accessed/received non-BIRP services.



Contribution of challenging behaviour to clinical informant stress

There was a significant relationship between challenging behaviour and the stress levels experienced by clinical informants. ($p<0.05$). As can be seen in Figure 13, clients rated as more stressful were more likely to have challenging behaviour. Over 90% of clients rated as causing severe levels of clinical informant stress had challenging behaviour.

Clinical informants' perception of client complexity

The relationship between perceptions of client complexity and challenging behaviour was statistically significant ($p<0.05$). The more complex clinical informants perceived clients to be, the more likely they had challenging behaviour. This relationship is depicted in Figure 14. Clinicians perceived those clients in remote geographical locations as more complex compared with their urban and regional counterparts (see Figure 15).

ADDITIONAL (NON-BIRP) SERVICE DELIVERY TO CHALLENGING BEHAVIOUR CLIENTS

Received and desired non-BIRP services

Clients with challenging behaviour received significantly more services than people without challenging behaviour ($p<0.05$) (figure 16). In addition, more additional services were desired for these clients with challenging behaviour than were accessed or received ($p<0.05$) (Figure 17).

A significantly greater proportion of clients with challenging behaviours received additional (non-BIRP) services including mental health, drug and alcohol, behavioural management, community agency/home support, legal, family/friend support and living skills training services compared with non-challenging clients ($p<0.05$). Other services were provided to an equivalent proportion of challenging and non-challenging clients.

Clients with challenging behaviour were also more likely to have a greater number of unmet needs (i.e. services desired but not provided) as identified by their clinical informants, compared with clients without challenging behaviour. This was a statistically significant finding for all services ($p<0.05$) except for physiotherapy, which showed a trend in this direction.

Overall, clients in remote areas had more unmet service need (median of three services) compared with clients in regional areas (median of one service), who in turn had more unmet need than clients in urban areas (median of nil services) ($p<0.05$). Figure 18 shows the services where there was a significant relationship between greater unmet need (desired non-BIRP services) and geographical location of clients with challenging behaviour.

Figure 17: Challenging behaviour by desired non-BIRP services.

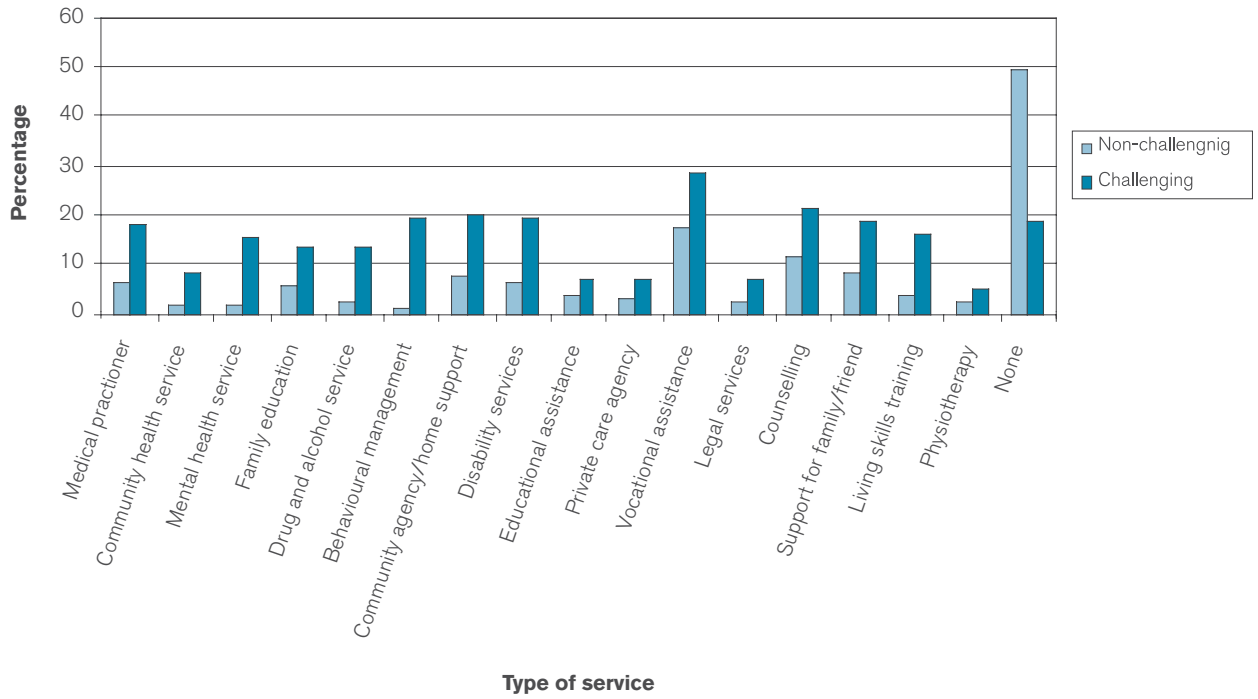
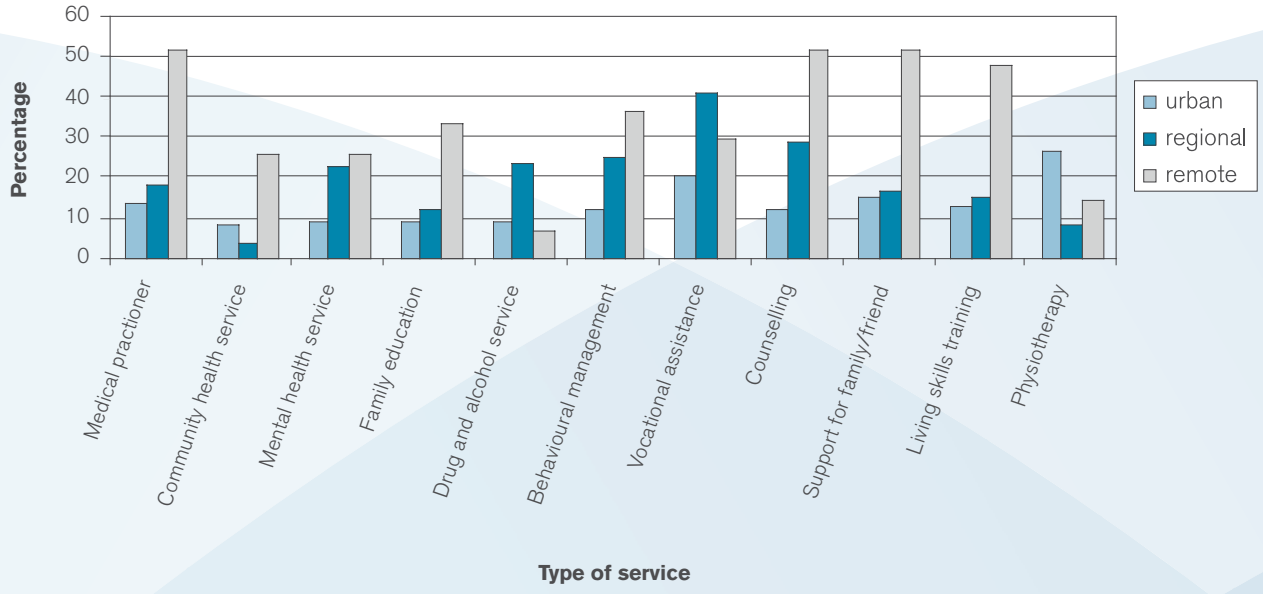


Figure 18: Desired non-BIRP services by location of challenging behaviour clients.



QUALITATIVE CASE REVIEW

The case review of 28 BIRP client histories led to the identification of 36 initial themes. An examination of these initial themes ascertained that some could be grouped together and some could be split over two themes. It was also found that some statements that comprised a theme did not shed any light on the challenging behaviour of the clients or the management of challenging behaviour per se. These latter themes were dropped. The end product was the identification of 24 themes reflecting issues pertinent to understanding the challenging behaviours seen in adult clients who sustained a TBI.

Theme clusters and individual themes

It is noteworthy that each of the case histories was a highly complex presentation of challenging behaviour and reflected the interplay of multiple themes. The identification and separation of themes was a means of making sense of this complex information. However, it was found that subgroups or clusters of themes could be identified. A summary of each cluster of themes is provided below (Figure 19).

Client characteristics

Both pre-and post- injury characteristics of the client contributed to challenging behaviour episodes. It was frequently found that clients prone to challenging behaviour post-injury had a pre-morbid history of poor behaviour regulation and a pre-injury history of high stress and reduced capacity to find suitable solutions to life problems. Pre-morbid drug and alcohol use and mental health problems persisted and contributed to the post-TBI challenging behaviours of clients. Other post-injury factors also conspired to affect adults' behaviour after TBI including cognitive impairments, disability, lack of insight/ motivation and perceptions of loss of control.

Family/carer issues

Families (parents, grandparents, partners, children) were found to be critical in the management and support of clients with challenging behaviour. Salaried attendant carers were often used to supplement the care provided by families, or in some instances were the primary avenue of care for the client. These people proved to play an important role in the type of environment they structured for the client, how they responded to challenging behaviours and how they interacted with BIRP to obtain external services and support required by the client. However, significant problems were encountered with family members and/ or carers not providing the environmental structure the client needed, not responding to challenging behaviours appropriately to minimise their recurrence, not maintaining a consistent approach to behaviour between carers, or not interacting with clients in such a way that the person with TBI continued to perceive they had control over their own lives. These difficulties were encountered despite efforts to educate and train families in implementing behaviour management programs.

Environmental (non-family) factors

A number of environmental factors contributed to the challenging behaviours observed in clients including: lack of services in remote parts of the state, especially psychological expertise for managing challenging behaviours; lack of a seamless system of case management and case co-ordination of clients engaged with other health services because of co-morbidity; and a lack of specialist respite services.

The case review also identified difficulty in finding suitable, supported accommodation in crisis situations, with clients needing to be readmitted to hospital or BIRP transitional living unit facilities as a result. Even when public housing was found, clients were shown to be at risk of losing their accommodation as a result of challenging behaviours, emphasising that the accommodation placement needs to be supported. There were also cases of young TBI clients in residential aged care facilities (nursing homes). The lack of age-appropriate directed care in these facilities was found to be a trigger for challenging behaviours, and when a client was placed in more age-appropriate accommodation, challenging behaviours ceased.

Another important environmental factor that contributed to the maintenance of challenging behaviour was the lack of participation opportunities. The case review found that even for clients with quite entrenched and long-established challenging behaviour patterns, the implementation of meaningful and supported participation was important in improving client self-esteem and reducing levels of frustration, resulting in a decline in challenging behaviour episodes. This opportunity to participate was sometimes found to be provided by respite services. However, this only worked when the respite services had staff with the experience to structure and provide the necessary supports for clients with challenging behaviour.

Medical issues

The case review revealed that medical problems and the stress associated with them can contribute to challenging behaviour.

The case review revealed significant mental health co-morbidity in the TBI population and this posed a challenge for managing problematic behaviour. However, there appeared to be no consistent referral pathway for accessing mental health services. Such services were sometimes provided by Area mental health teams whereas at other times mental health problems were treated by general practitioners, rehabilitation specialists, private psychiatrists, BIRP psychologists or some combination of these.

Some challenges were identified in the provision of mental health services including insufficient level of servicing and follow-up, refusal of patients to deal with mental health issues, and the client's geographical location making it difficult to access such services. Mental health services also did not always engage with clients because they had a TBI diagnosis, expecting brain injury services to take responsibility for mental health issues.

Drug and alcohol problems interfered with client engagement with rehabilitation programs and were significant contributors to challenging behaviour. However, there was also significant unmet need for D&A treatment.

Figure 19: Thematic cluster from qualitative case review.

Client characteristics
- The experience of loss of control by clients can trigger challenging behaviour
- Drug and alcohol/mental health co-morbidity contributes to challenging behaviour
- Challenging behaviours become entrenched over time
- Pre-morbid level of functioning contributes to challenging behaviour post-TBI
- Client lack of insight and motivation to change can interfere with attempts to manage challenging behaviour
- Catering for impairment/disability of clients is important for management of challenging behaviours

Family/Carer issues
- Lack of family/partner support promotes challenging behaviour
- Inconsistent management approaches maintain challenging behaviour
- Problems with attendant care services can maintain challenging behaviours
- Appropriate responses to behaviour are an important way to manage challenging behaviour

Environmental factors (non-family)
- Accommodation/residential issues can contribute to challenging behaviour
- Lack of co-ordinated care by different service providers can impact on behavioural management
- Lack of BIRP support for challenging behaviour clients in remote areas
- Limited psychological support for challenging behaviour clients
- Limited speciality respite
- Supported, meaningful participation can reduce challenging behaviours

Medical issues
- Lack of support for mental health co-morbidity
- Lack of support for co-morbid drug and alcohol issues
- Managing complex medical issues assists in the management of challenging behaviour

The barriers to obtaining such treatment were unclear but there was suggestion clients in some instances may be refusing such service, which was consistent with clients receiving D&A services as a result of court orders rather than from voluntary engagement with D&A programs.

Consequences of challenging behaviour

Clients with TBI can experience significant social consequences as a result of challenging behaviour, including withdrawal of friends, exclusion from activities of interest and loss of important services. Challenging behaviour was a significant factor leading to carer burn-out, and this scenario could lead to a loss of accommodation because of family reaching the point of not being able or willing to provide care or have the client live in the same house. Challenging behaviour also predisposed clients to have contact with the criminal justice system. Attempts were made to keep clients out of the criminal justice system via court-ordered bonds to behave appropriately. However, the effectiveness of such bonds depended on how well clients were monitored and whether breaches were reported.

DEVELOPMENT & MAINTENANCE OF CHALLENGING BEHAVIOURS

CONSEQUENCES OF CHALLENGING BEHAVIOUR

Exclusion of participation/decline in family adjustment/ accommodation issues/contact with criminal justice
- Challenging behaviour increases risk of family/partner burn-out
- Behaviour can lead to contact with the criminal justice system
- The relationship between challenging behaviour and participation is bi-directional
- The relationship between challenging behaviour and social isolation is bi-directional
- Lack of peer group can encourage and promote challenging behaviours
- Challenging behaviour can result in a loss of important services for clients

CONCLUSION

The BIRP model of service delivery aims to put in place the necessary supports and rehabilitation options so clients can live successfully in the community. This is reflected in the BIRP mission statement, which outlines the following objectives:

- To provide assessment, rehabilitation and community support service for the present and future needs of children, young people and adults with traumatic brain injuries and their families
- Establish and develop specific rehabilitation programs to enable maximum reintegration of people with traumatic brain injury into the community in line with the needs and preferences of each individual
- Provide a goal-directed individual management system for the client and to minimise dependency and maximise function
- Advocate for, initiate and support the development of appropriate policies and services in the government and community sectors to meet the long-term needs of people with traumatic brain injury and their families
- Assist people with traumatic brain injury and their families though advice, information, discussion and counselling during medical, rehabilitation and community support phases
- Increase community awareness of the particular problems faced by the person with traumatic brain injury and his or her family
- Undertake research and education about traumatic brain injury
- Provide consultation and support to other service providers in the area of traumatic brain injury management.

This focus on community integration mirrors what has occurred in other parts of Australia and the trend internationally (Feeney, Ylvisaker, Rosen & Greene, 2001; Kelly & Winkler, 2007).
The results of the current study emphasise the need for this community-based model of care to follow eight key principles to achieve better outcomes for clients with, or at risk of developing, challenging behaviour:

PRINCIPLE 1:

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

The CBP identified a very high prevalence of challenging behaviour in the active adult BIRP cohort; 53% of BIRP adult clients with TBI met the study criteria for challenging behaviour.

The qualitative case review showed how entrenched patterns of challenging behaviour can develop after TBI when there have been no previous attempts at behavioural management.

It was typical that the stress and despair experienced by carers prompted them to seek BIRP input in trying to handle challenging behaviour (up to 20 years after the TBI was sustained in some cases).

Such cases were difficult for BIRP to treat as many years of problematic behaviour, family/carer habitual responses and/or behaviour-maintaining environments needed to be undone.

Identifying those clients at risk of challenging behaviour is important for delivering early intervention services. The CBP found there were six clinical variables that could distinguish, with 75% accuracy, challenging from non-challenging clients: pre-injury alcohol problems; current drug and alcohol problems;, level of cognitive impairment; severity of depressive symptoms; severity of other mental health problems; and level of disability. Appendix E shows how the statistical parameters of this model could be used to identify clients at higher risk of developing challenging behaviour.

These results reveal that BIRP needs to increase its capacity for early detection of challenging behaviour so that intervention services can be promptly delivered before problems become entrenched. In addition, BIRP needs to ensure the ongoing monitoring of patients with challenging behaviour so that ineffective behavioural management approaches can be identified promptly and new strategies devised. The following is recommended:

Recommendation 1:

BIRP services to have a system of assessment and monitoring for clients with TBI 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 maintaining 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

The CBP showed that cognitive impairment and level of disability were instrumental in differentiating challenging from non-challenging behaviour clients. Cognitive impairment increased the odds of having challenging behaviour by up to four-and -a-half times, while disability increased the odds of challenging behaviour by up to eight times. Moreover, all 28 clients included in the qualitative review provided real examples of how impairment, disability, medical issues and/or complications contributed to challenging behaviour presentation.

Given that clients with challenging behaviour had a greater level of impairment and disability, more staff from BIRP interdisciplinary teams were expected to be involved in their management. It was generally the case that two-thirds of challenging and non-challenging clients accessed BIRP rehabilitation specialists and case managers. Psychologists and social workers were more likely to see challenging than non-challenging behaviour clients, but only some 35% of challenging behaviour clients received these important services. Other BIRP professionals (e.g. occupational therapy, speech pathology, recreational therapy) were no more or less likely to be providing services to challenging clients. Overall, it was found that challenging and non-challenging clients engaged with a similar number of BIRP professionals, despite the former group's greater level of impairment and disability. Instead it was found that challenging behaviour clients accessed more non-BIRP services than non-challenging clients.

The CBP did not set out to investigate the reasons why BIRP services were not provided to clients, but the qualitative review did provide two possible explanations. Specifically, the qualitative review found that some clients may not engage with BIRP professionals because of reduced insight into their need for such services and/or clients' reduced motivation to engage with services. Also, BIRP was not sufficiently resourced to provide a complete package of rehabilitation services in regional and remote parts of the state (see Principle 5 below).

BIRP needs to reappraise its delivery of therapy services to clients who demonstrate, or are at risk of, challenging behaviours. The results of the CBP suggest that challenging behaviour clients may not be receiving the BIRP services they need. Although lack of motivation and insight are challenges in working with clients, BIRP staff should take active steps to promote client insight and motivation (e.g. use of motivational interviewing). There also needs to be recognition that therapeutic alliances between staff and clients may take time to develop. The following is recommended:

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 are recognised as the context of 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 levels of long-term care, support and environmental modification

The CBP showed that there was a significant burden placed on the community in the care of challenging behaviour clients. Approximately 75% of clients with high (daily) care and support needs and 50% of clients with intermediate (less than daily) care and support needs had challenging behaviour, compared with 30% of clients who had no care and support needs.

The case review found that the home environment was particularly important in the delivery of needed care and support services. The review found that, in isolation, families struggled or demonstrated a complete inability to provide the supportive, consistent structure, feedback and environment required for clients with challenging behaviour. The results of the CBP showed there was greater unmet need for family education amongst challenging behaviour clients. However, the qualitative review found that education about behavioural management alone was not a sufficient way of imparting skills about how families/carers can mange challenging behaviour; some families required time to practice implementation of strategies under supervision. This was also consistent with the CBP result showing greater unmet need for family and friend support and community agency/home support for clients with challenging behaviour than for clients without challenging behaviour.

The need for this support to be provided on a long-term basis was supported by results revealing the stability of challenging behaviour in the TBI population over time. The CBP found the prevalence of challenging behaviour to be stable over a short three-month follow-up interval. Baguley, Cooper & Felmingham (2006) studied the prevalence of aggression after TBI and found stability in prevalence over a five-year follow-up interval.

BIRP services need to reduce the unmet need of clients with, or at risk of developing, challenging behaviour. This includes providing greater in-home training and support to families/ attendant carers about behavioural management approaches and ensuring the transfer of training to real life situations. The following is recommended:

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/day, 7 days/week support and supervision.

Recommendation 11:

There is a need to increase available community-based alternatives to family care 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 clients who have TBI.

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)

The CBP found convincing evidence of the relationship between challenging behaviour and mental health, drug and alcohol co-morbidity. The qualitative case review showed how these co-morbidities contributed to and compounded the challenging behaviours observed in clients with TBI. The CBP also found that whilst accommodation/residential issues, poor participation and more isolated geographical living were generally associated with greater rates of challenging behaviour overall, male clients or clients of Aboriginal and/or Torres Strait Islander origin were more likely to demonstrate specific types of challenging behaviours. Males were more likely to demonstrate higher rates of prevalence of verbal aggression, physical aggression against objects, absconding/wandering and socially inappropriate behaviour, whereas those of indigenous heritage were more likely to abscond/wander.

The qualitative review also found there was a complex milieu of pre-existing and concurrent conditions that contributes to challenging behaviour, including poor family dynamics, limited level of home and community support, forensic issues, poor education, inadequate living arrangements, health problems, poor participation, social isolation, lower socio-economic status and lack of patient insight and/or motivation.

To manage the myriad factors that contribute to and maintain challenging behaviour, these clients received significantly more non-BIRP mental health, drug and alcohol, behavioural management, community agency/home support, legal, family/friend support and living skills training services compared with non-challenging behaviour clients. Nevertheless, clients with challenging behaviour demonstrated significantly greater level of unmet need for these services as well compared with non-challenging behaviour clients.

These results emphasise that any model of care developed for the TBI population must recognise the broader psychosocial and environmental context in which challenging behaviours occur, of which drug and alcohol, mental health and cognitive problems and disability are an important but only limited part, and strategies need to be developed to ensure clients' needs for services to tackle these issues are met. The following is recommended:

Recommendation 14:

BIRP staff need to advocate for access to, and provide support for individual clients to access, D&A and mental health services.

Recommendation 15:

BIRD needs to develop and support state-wide education programs for D&A and mental health services staff to increase their awareness of issues relevant to the TBI population and their ability 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 people with TBI 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. D&A; mental health).

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 BIA to explore options about advocacy 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 NSW based on need

The CBP found a greater prevalence of challenging behaviour in regional/remote parts of the state (approximately 60%) compared with urban geographical locations (50%). Additionally, there was greater unmet need in remote and regional parts of the state for accessing services than in urban areas. Remote and regional clients had unmet need for a median of three and two services, respectively. Urban clients, in contrast, had unmet need for a median of nil services.

Unfortunately, BIRP was unable to service the greater unmet need in regional/remote areas because of a lack of resources. BIRP was better able to provide professional services to clients located in urban regions than clients located in regional and, especially, remote areas. Specifically, social work, clinical psychology, physiotherapy, diversional therapy, speech pathology and rehabilitation medicine were more likely to be available for urban clients whether they displayed challenging behaviour or not.

BIRP units located in regional and remote areas typically do not have the multi-disciplinary teams that exist in urban BIRP units. This resulted in remote clients receiving a case management model of care rather than services from different BIRP professions to address specific rehabilitation issues. This created a greater burden for the BIRP clinician involved in case management. The CBP found that challenging behaviour was associated with higher levels of clinician stress and the additional burden of clients being located in remote parts of the state added to the perceived complexity of the client.

Another issue in the qualitative review related to the lack of availability of transport in more remote parts of the state and financial hardship, making it difficult for geographically isolated clients to access services.

Both BIRP and non-BIRP service providers need to develop their service models so they are adequately delivered to clients in more remote parts of the state. Currently, there is a geographic inequity in service delivery and greater burden on clinicians whose caseload comprises proportionally more geographically isolated clients. The following is recommended:

Recommendation 21:

BIRP services that cater for remote clients need to have the option of providing a transitional living program (7 days per week), develop linkages within the network and/or for there to be an increase in resources 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, and clinical neuropsychology).

Recommendation 25:

BIRP needs to increase the use of IT facilities for clinical service consultations (e.g. rehabilitation specialists, clinical psychologists) and for the management for 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 services

The qualitative study provided clear case examples where communication and coordination was required between BIRP and services such as other medical health providers; drug and alcohol services; mental health services; the police and criminal justice system; and accommodation services.

The consequences of an absence of, or lack of communication between, services included medical practitioners and services withdrawing provision of care because of client behaviour; clients with substance abuse issues not receiving any formal drug and alcohol services; mental health services not initiating assessment and treatment or providing sufficient follow-up to clients with mental health disorders; public housing authorities providing clients with inappropriate housing options given the client's support requirements; police not understanding how to interact with TBI clients; and lack of follow-up and consequences of bond breaches reinforcing clients' challenging behaviour.

These results reveal that greater advocacy and education need to be provided to non-BIRP services regarding TBI and challenging behaviour. BIRP also needs to ensure staff are proactive in the initiation and maintenance of client-centred communication pathways with other non-BIRP service providers. The following is recommended:

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 inter-agency case conferencing for management of complex clients.

Recommendation 27:

BIRP to increase understanding of the monitoring process of people on court-ordered bonds, and who to contact in cases of bond breaches to increase the effectiveness of these strategies in managing challenging behaviour.

Recommendation 28:

BIRP staff to identify clients in contact with police and liaise with local police 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

The qualitative case review showed that behaviour management programs implemented by BIRP psychologists are effective for challenging behaviour management. Two evidence-based behavioural management approaches were used in this regard including traditional behavioural modification and positive behavioural support.

Traditional behavioural modification techniques attempt to ensure the consequences of an individual's behaviour are such that the likelihood of appropriate behaviour will increase and the likelihood of inappropriate behaviour will decrease. Behaviour modification techniques are based on operant methods of behavioural psychology, utilising positive reinforcement as the primary agent for achieving change (Alderman, 2007; Eames & Wood, 1985).

Positive support oriented interventions for challenging behaviour focus on broad, antecedent manipulations, balanced with natural consequences, rather than manipulation of artificial consequences (Ylvisaker, Jacobs & Feeney, 2003). In this approach, controlling the environment and inducing positive settings (i.e. the antecedents of behaviour) are seen as equally important as altering the consequences of behaviour. Zencius, Wesolowski, Burke & McQuade (1989) showed the effectiveness of tackling challenging behaviour using positive behavioural supports in a client who previously did not respond to traditional operant methods of behavioural modification.

In the community setting, there is evidence that positive behavioural supports may be superior to the sole use of consequence-based behaviour management approaches and this is likely related to the nature of the neuropsychological deficits of clients who sustain TBI (Feeney et al., 2001).

In addition to behavioural models of treatment, provision of individual and group-based approaches is considered important in the context of making a broad range of available treatment options available, depending on the needs of the client. For example, group-based treatment of anger management difficulties in community-based clients has demonstrated effectiveness in the Australian setting (Walker, Nott, Doyle, Onus, McCarthy & Baguley, 2010).

The qualitative case review found problems, however, in implementation of evidence-based behavioural management approaches, including family and carers not following the behaviour management programs in a consistent fashion and the inappropriate utilisation of punishment, which undermined formal behavioural management programs. In addition, there were examples where non-psychologist BIRP staff struggled with implementation of behaviour management programs including using inappropriate rewards and consequences for behaviour, resulting in an escalation of behavioural problems.

Evidence-based practice must inform the treatments and approaches used to manage challenging behaviour. It is clear that families/carers need more support to follow behavioural management programs (see also Principle 2 above) and all behavioural management programs developed in BIRP need to have psychology input. The following is recommended:

Recommendation 29:

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

Recommendation 30:

Continue use of TLP/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 when the family arrangement has been identified as sustainable.

Recommendation 31:

BIRD to implement standardised education to all staff about best practice and 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

The CBP showed that low participation was strongly related to challenging behaviour. Whilst only 17% of clients with good

levels of participation had challenging behaviour, 85% of clients with poor levels had challenging behaviour.

The qualitative review showed that clients with challenging behaviour are at risk of being excluded from social and community activities when they do not receive an adequate level of support. Additionally, supported participation that was of intrinsic value to the client and viewed as meaningful was able to reduce challenging behaviour episodes. Boredom or activities that lacked meaning to the client were underlying causes of challenging behaviour.

The work of Ylvisaker and his colleagues (Feeney et al., 2001; Ylvisaker et al., 2003) emphasised the importance of participation in the management of challenging behaviour in the positive behavioural supports framework. Specifically, the positive behaviour process first reduces handicap by providing the required supports for meaningful participation. The patient practises strategic behaviours in the context of the supports provided to reduce disability, and over time these strategic behaviours may become internalised and, therefore, reduce underlying impairment. By starting with participation (i.e. reducing handicap) patients experience success with the rehabilitation process that they perceive as meaningful, increasing the clients' probability of engagement with the rehabilitation process. Feeney et al. (2001) demonstrated the cost-effectiveness of a positive behavioural supports approach that emphasised client participation in reducing challenging behaviour.

These results emphasise the importance of implementing supported participation for clients who have, or are at risk of developing, challenging behaviours. The following is recommended:

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/or 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 for undertaking of therapies that will assist clients in 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.

Recommendation 41:

A Behaviour Support and Development Service (BSDS) needs to be established as the most practical and efficient method of ensuring a planned and integrated application of the above eight principles and recommendations across the current BIRP network.

IMPLEMENTATION OF PRINCIPLES

The scope of the recommendations arising from the identified principals requires a planned and integrated approach to implementation.

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 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:

- Comprehensive assessment of the needs of clients with, or at risk of developing, challenging behaviour
- Development of comprehensive behaviour management plans
- Implementing intensive behaviour programs with individuals in a range of different community living situations (eg mentoring) in certain circumstances
- Provision of support and supervision to families, ancillary carers and BIRP staff implementing behavioural management programs
- Imparting the knowledge and skills required by families, ancillary carers and BIRP staff about TBI and challenging behaviour

- Education and support of other providers (mental health; D&A; housing; disability services; police) so they can initiate and maintain services needed by clients with TBI
- Develop and support of participation opportunities for clients with, or at risk of developing challenging behaviour

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.

Service delivery recommendations focus on better utilisation of existing staffing, technologies and infrastructure so that service needs for clients with or at risk of challenging behaviour are met. Workforce recommendations will require investment to increase resources so the service needs of challenging behaviour clients can be met. Workforce recommendations will also require greater investment in developing and implementing training programs. Policy changes will ensure that an enduring philosophy is developed across different service providers for the long-term achievement of client service needs.

Table 6: Areas targeted by recommendations

	BIRD	BIRP	Non-BIRP
Service Delivery	6, 29	1, 3, 4, 5, 7, 8, 9, 14, 19, 21, 26, 28, 30, 33, 34, 35, 36, 37	38, 40
Workforce			
Resources	41	22, 23, 24, 25	
Training	15, 16, 17, 18, 31	27, 32	
Policy	2, 10, 11, 20	39	12, 13

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 (e.g. case managers, therapists and rehabilitation specialists).

In addition, the Service would be expected to co-ordinate and evaluate BIRP behavioural management strategies.

This would specifically involve:

- Continual evaluation and monitoring of the behavioural management services across the state,
- State-wide co-ordination of behavioural management practices across the BIRP
- Development and implementation of standards and policies.

Table 6 provides an organised structure of the recommendations arising from this project, including the establishment of a Behaviour Support and Development Service. This structure provides an outline of the areas the recommendations target at the level of the BIRD, BIRP and non-BIRP service providers for Service Delivery; Workforce resources and training and Policy.

It is anticipated that the next phase of the Challenging Behaviours Project will be the implementation of the current recommendations in adult services. This could include funding a project officer or forming a working group within BIRP to review the recommendations and develop strategies for implementation. BIRD will need to develop and obtain executive approval for a work plan to adopt the principals and implement the recommendations for Service Delivery, Workforce and Policy.

SUMMARY

The CBP established the prevalence, course, co-morbidity and burden of challenging behaviours in adult BIRP clients with TBI. These results informed the development of eight principles to guide clinical practice and 41 recommendations for changes or enhancement to the existing model of service delivery for clients with or at risk of demonstrating challenging behaviour.

It was suggested that establishing a Behaviour Support and Development Service within the BIRP is the most practical way to ensure the principles and recommendations are adopted and implemented.

APPENDIX A

The following pages contain the forms of the seven surveys used in the CBP.

Overt Behaviour Scale©
(2005. Research version)

Challenging behaviours

Behaviours can be challenging or problematic if they are disruptive, make the client or other people uncomfortable, or go against the rules of community living. Such behaviours lead to an experience of distress or can disrupt things like social relationships and continuance of services. They can also result in significant financial cost to the service system.

What is this questionnaire for?

This questionnaire is designed to clarify the types of observable behaviours that can occur following acquired brain injury (ABI). This can help to show how behaviours may have changed over time and can inform decisions related to clinical interventions. This scale can also be used to measure the frequency of challenging behaviours and the impact that they have on people living and/or working with the client (including family members and service providers).

What does this questionnaire measure?

There are 9 types of behaviour that can be scored on this scale; they are:

- Verbal aggression
- Physical aggression – against objects, against self, against other people
- Inappropriate sexual behaviour
- Perseveration / repetitive behaviour
- Wandering / absconding
- Inappropriate social behaviour
- Adynamia / lack of initiation

It enables you to score the severity, frequency, and impact of each behaviour.

How to use this questionnaire

For each of the 9 types of behaviour there is a heading (e.g., verbal aggression) and a relevant subscale. If your client exhibits no sign of a behaviour, mark the "no" box and go to the next behaviour.

If your client does show this type of behaviour you need to complete the subscale. Here you can indicate more clearly what sort of behaviour occurs. Under each heading there are a number of behaviour descriptions with realistic examples that correspond to increasing levels of severity (shouting is low severity, threats are more severe). Tick each of the types of behaviour observed and rate how frequently they occur and the impact that they have.

★ *Rate a behaviour only once. If a behaviour appears to fit 2 subscales, use the single most appropriate subscale.*

Timeframe

This scale represents behaviour that has occurred over the most recent 3 months.

More information

Developmental and psychometric information regarding the OBS has been published in ……..

Complete instructions, 'frequently asked questions', and scoring advice have been published in ……

Date of completing OBS_____

Client name _____

Informant(s) _____

How to rate behaviours using OBS

Tick each level that is a problem

For each type of behaviour there are a number of descriptions with examples that illustrate different levels of severity. Select the level(s) with a description or example that best represents the sorts of behaviour(s) that you have observed by placing a tick (4) in this column.

Remember, these behaviours are only examples; if you have seen behaviours that are similar, but are not exactly the same, then tick this description.

Frequency

Rate how frequently the behaviour occurs using a number from 1 to 5 with the following definitions:

1 = less often than once per month
2 = once a month or more
3 = once a week or more
4 = once a day
5 = multiple times each day

Impact (distress or disruption)

"Impact" means the amount of emotional distress and/or practical disruption that a challenging behaviour causes. For example, "impact" refers to your experience of stress, worry, concern, or fear as a result of the behaviour. But "impact" can also refer to practical difficulties including carer burnout or injury, needing additional staff, altered procedures, dealing with complaints from families or other residents, or having to acquire additional supports such as psychiatrists, police, or ABI consultants. Disruption often translates into additional costs.

Rate how much this behaviour impacts upon yourself and/or other people by using a number from 1 to 5 and the following definitions:

1 = no impact
2 = minor impact
3 = moderate impact
4 = severe impact
5 = extremely severe impact

VERBAL AGGRESSION Has the client shown any verbal aggression? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	**Severity**	**Levels** Tick each level that is a problem (4)	**Frequency** **(rate 1 … 5)** 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	**Impact** **(rate 1 … 5)** 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Makes loud noises, shouts angrily, is clearly not directed at some other person (e.g., "bloody hell!")	1			
Makes mild personal insults clearly directed at some other person but does not include swearing/offensive sexual comments (e.g., "You are stupid!", "idiot".).	2			
Swearing, use of foul language, moderate threats clearly directed at others or self (e.g., "F_ _ _ off you bastard!").	3			
Makes clear threats of violence directed towards others or self (e.g., "I'm going to kill you!" or "I'm going to finish myself!") or requests help to control self (i.e., expresses anxieties that they will engage in aggressive act beyond own control unless someone make some immediate intervention). This includes suicidal threats.	4			

PHYSICAL AGGRESSION Has the client shown any physical aggression? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	**Severity**	**Levels** Tick each level that is a problem (4)	**Frequency** **(rate 1 … 5)** 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	**Impact** **(rate 1 … 5)** 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Physical aggression against objects				
Slams doors, scatters clothing, makes a mess in clear response to some antecedent.	1			
Throws objects down (without some other person at risk of being hit by the object), kicks furniture without breaking it, marks the wall.	2			
Breaks objects, smashes windows	3			
Sets fire, throws objects dangerously (i.e., some other person is at risk of being hit by the object(s) thrown but is not actually hit) *If the object thrown does hit someone score this as* ***Physical aggression against other people***	4			
Physical acts against self				
Picks or scratches skin, hits self, pulls hair (with no or minor injury only).	1			
Bangs head, hits fist into objects, throws self onto floor or into objects (hurts self without serious injury).	2			
Inflicts small cuts or bruises, minor burns to self.	3			
Mutilates self, causes deep cuts, bites that bleed, internal injury, fracture, loss of consciousness, loss of teeth. This includes suicide attempts.	4			
Physical aggression against other people				
Makes threatening gesture that is clearly directed towards some other person, swings at people, grabs at clothes.	1			
Strikes, kicks, pushes, pulls hair (without significant injury) to person(s) aggression directed at.	2			
Attacks others, causing mild-moderate physical injury (bruises, sprain, welts) to person(s) aggression directed at.	3			
Causes severe physical injury (broken bones, deep lacerations, internal injury) to person(s) aggression directed at.	4			

INAPPROPRIATE SEXUAL BEHAVIOUR Has the client shown any inappropriate sexual behaviour? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	**Severity**	**Levels** Tick each level that is a problem (4)	**Frequency** **(rate 1…5)** 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	**Impact** **(rate 1…5)** 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Sexual talk • Comments of a sexual nature (e.g., "I've got a big dick", "I want to make babies with you", "You've got nice tits", "I could give you a good time") where comments may be face-to-face or in the form of phone calls or letters. • Explicit accounts of sexual activities (e.g., "When I am with a woman I like to . . . .")	1			
Touching (non genital) • Touching other people who do not want to be touched (but contact does not involve genitals). For example kissing hand or arm, putting arm around shoulder, patting someone's knee, rubbing or caressing arm or leg or back. • Also includes touching clothing (e.g., lifting skirts)	1			
Exhibitionism • "Flashing", exhibiting genitals, undressing in public. • Failing to dress (e.g., Walking about house without clothes on when coresidents could be or are present. Answering door when naked).	2			
Masturbation • Masturbation in a public or shared setting when other people are in the area. (e.g., masturbating in a car in a public carpark where passers by may see; masturbating in a common area in a supported residential setting.).	2			
Touching (genital) • Touching (or making attempts to touch) other people's breasts, buttocks, or genitals (e.g., groping staff who walk by, fondling breasts of support workers, pulling other's hands toward own groin).	3			
Coercive sexual behaviour, Rape • Attempt to forcibly undress another person. • Use of threat to obtain sex. • Sexual penetration of another person who has not consented	4			

Victim details can be noted here (The legal consequences of inappropriate sexual behaviour can differ depending on the sex and age of the victim.)

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PERSEVERATION / REPETITIVE BEHAVIOUR Has the client shown any perseverative behaviour? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	**Severity**	**Levels** Tick each level that is a problem (4)	**Frequency** **(rate 1 … 5)** 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	**Impact** **(rate 1 … 5)** 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Engages in prolonged continuation and repetition of a behaviour that has not resulted in physical harm (e.g., continued, persistent tapping, writing same letter over and over, unrolling entire toilet roll, asking the same question repeatedly: "do you watch the Bill?", "Will you marry me?")	1			
Engages in prolonged continuation and repetition of a behaviour that has resulted in minor physical harm (e.g., continued, persistent touching, rubbing, or scratching leading to skin irritation; remaining in shower until skin is shriveled)	2			
Engages in prolonged continuation and repetition of a behaviour that has resulted in serious harm (e.g., continued, persistent eye rubbing; riding an exercise bike and only stopping upon exhaustion)	3			

WANDERING / ABSCONDING Has the client shown any wandering/absconding? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	**Severity**	**Levels** Tick each level that is a problem (4)	**Frequency** **(rate 1 … 5)** 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	**Impact** **(rate 1 … 5)** 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Going into areas that are prohibited but where there no or low risk of harm (e.g., entering other resident's rooms, staff areas, kitchen)	1			
Leaving the familiar, 'safe', environment when there is a good risk of becoming lost or seriously harmed (e.g, nursing home resident attempting to return to family home, walking onto freeways, needing to be located/recovered by police)	2			
Escapes secure premises (e.g., through a doorway left open, by using security door codes, by climbing over fence). May physically resist attempts to stop such escape (e.g., wrestles with or pushes staff who attempt to stop or restrain them).	3			

INAPPROPRIATE SOCIAL BEHAVIOUR Has the client shown any inappropriate social behaviour? NO ρ (go to next behaviour) YES ρ (rate the subscale below)	Severity	Levels Tick each level that is a problem (4)	Frequency (rate 1 … 5) 1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	Impact (rate 1 … 5) 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
Socially awkward · Inappropriate laughter. · Failure to monitor personal hygiene (e.g., does not shower regularly). · Excessive apologising or thanking · Standing too close to strangers · Failure to pick up on nonverbal cues (that others are bored, the joke was not funny, the conversation is over)	1			
Nuisance / annoyance · Interrupts other people's conversations · Actively does things to seek attention (e.g., spills food, rings buzzer, "Nurse, can you come here?") · Inconsiderate of other people (e.g., hogging TV channel or remote control) · Nagging, impatient (e.g., always wanting something else to be done; can not tolerate waiting for supermarket queues) · "Butts in" to other people's affairs. (e.g., advising staff/management on how to improve residence, reporting on other clients' activities.)	2			
Noncompliant / oppositional · Responds "no!" to prompts to do things. Refuses to discuss problem behaviours with staff. · Will not follow toilet or shower routines. Refuses to take medication. · Rejects or dismisses service providers who are helpful with home care. · Intentional lying that is not due to poor memory (e.g., denying drug use or stealing; fabricating stories to cover tracks) · Will not (as opposed to Can not) follow rules. (e.g., leaving without telling someone where s/he is going)	3			
Petty crime or Unlawful behaviour · Driving while unlicensed · Fraud (e.g., writing dishonoured cheques) · Obtains goods by theft or deceit · Stealing (e.g., steals cigarettes from other residents, steals clothes or food from shops; materials from building sites)	4			
Presents a danger/risk to self or others · Lights fires inappropriately. (e.g., smoking in room, burning rubbish in bin, starting bonfire near gas cylinder) · Crosses road without evaluating traffic. Wheeling wheelchair in middle of road. · Climbs ladders when perception and / or balance impaired · Excessive use of alcohol, cigarettes, or other substances where that is the key behaviour leading to risk or actual harm to self or others. · Uses provision of sex to gain access to goods (such as money, cigarettes, drinks) or services.	4			

Adynamia / Lack of initiation

EXPLANATION

This behaviour is different from the others because it is a lack of overt behaviour.

Adynamic behaviour is characterised by a lack of motivation, initiative, or interest in day-to-day activities.

The person has difficulty getting tasks started.

For example, they may not wash, eat, or drink, shower or groom themselves without prompting from others.
They may sit on the couch all day, not initiate social conversation or attend social activities without someone taking them.
The person may engage in activities if someone else prompts them.

Adynamia / Lack of initiation Has the client shown adynamia / lack of initiation? NO ρ (questionnaire complete) YES ρ (rate the subscale below)	Severity *i.e., Amount of prompting required* (rate 1 … 5) 1= less than once/day 2= approx. once/day 3= more than twice/day 4= many times/day 5= all tasks, everyday	Impact (rate 1 … 5) 1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
More examples • Once asked to "wash the dishes", the person may then commence and complete the task. • Some people need more prompts: they might only wash dishes and then need another prompt for cutlery: "okay, you've finished the plates, what about the cutlery"? • In severe cases, a person may not eat despite having a meal placed in front of them or fail to wash himself or herself even if standing under the shower. They would require constant prompts such as "put some soap on the washer, soap up your arms, now rinse etc".		

Patient Name_____

Rater_____

Date Completed_____

Disability Rating Scale (DRS)

Arousability, Awareness, & Responsivity

Eye Opening
- ❑ 0 Spontaneous
- ❑ 1 To Speech
- ❑ 2 To Pain
- ❑ 3 None

Communication Ability
- ❑ 0 Oriented
- ❑ 1 Confused
- ❑ 2 Inappropriate
- ❑ 3 Incomprehensible
- ❑ 4 None

Motor Response
- ❑ 0 Obeying
- ❑ 1 Localizing
- ❑ 2 Withdrawing
- ❑ 3 Flexing
- ❑ 4 Extending
- ❑ 5 None

Cognitive Ability for Self Care Activities

Knows how and when to feed, toilet or groom self

Feeding
- ❑ 0.0 Complete
- ❑ 0.5
- ❑ 1.0 Partial
- ❑ 1.5
- ❑ 2.0 Minimal
- ❑ 2.5
- ❑ 3.0 None

Toileting
- ❑ 0.0 Complete
- ❑ 0.5
- ❑ 1.0 Partial
- ❑ 1.5
- ❑ 2.0 Minimal
- ❑ 2.5
- ❑ 3.0 None

Grooming
- ❑ 0.0 Complete
- ❑ 0.5
- ❑ 1.0 Partial
- ❑ 1.5
- ❑ 2.0 Minimal
- ❑ 2.5
- ❑ 3.0 None

Dependence on Others

Level of Functioning

Physical & cognitive disability

- ❑ 0.0 Completely Independent
- ❑ 0.5
- ❑ 1.0 Independent in special environment
- ❑ 1.5
- ❑ 2.0 Mildly Dependent-Limited assistance
  Non-resident helper
- ❑ 2.5
- ❑ 3.0 Moderately Dependent-moderate assist
  Person in home
- ❑ 3.5
- ❑ 4.0 Markedly Dependent
  Assistance with all major activities, all times
- ❑ 4.5
- ❑ 5.0 Totally Dependent
  24 hour nursing care

Psychosocial Adaptability

Employability

As full time worker, homemaker, student

- ❑ 0.0 Not Restricted
- ❑ 0.5
- ❑ 1.0 Selected jobs, competitive
- ❑ 1.5
- ❑ 2.0 Sheltered workshop, Noncompet.
- ❑ 2.5
- ❑ 3.0 Not Employable

Total Score (sum all scores) _____

Revised 2/99 Santa Clara Valley Medical Center

HoNOS-*ABI*
Health of the Nation Outcome Scales for *Acquired Brain Injury*

Summary of rating instructions:

1. Rate each scale in order from 1 to 12

2. Do not include information rated in an earlier item except for item 10 which is an overall rating

3. Rate the MOST SEVERE problem that occurred during the previous 2 weeks

4. All scales follow the format

0 = No problem
1 = minor problem requiring no action
2 = mild problem but definitely present
3 = moderately severe problem
4 = severe to very severe problem

Rate 9 if not known

1. Active Disturbance of Social Behaviour e.g. overactive, aggressive, disruptive or agitated behaviour, uncooperative, resistive, or disinhibited behaviour.
- include such behaviour due to any cause. This scale rates antisocial acts. Rate passive disturbance of social behaviour, eg. social withdrawal, under scale 9 or 10. Do not include bizarre but non-aggressive behaviour which is probably or definitely attributable to hallucinations or delusions, rated at Scale 6.

0 - No problems of this kind during the period rated.
1 - Occasional irritability, quarrels, restlessness etc., but generally calm and co-operative and not requiring any specific action.
2 - Includes aggressive gestures, e.g. pushing or pestering others and/or verbal threats or aggression; lesser damage to objects/property (e.g. broken cup, window); significant overactivity or agitation; intermittent restlessness and/or wandering (day or night); uncooperative at times, requiring encouragement and persuasion.
3 - Physically aggressive to others (short of rating 4); more serious damage to, or destruction of, property; frequently threatening manner; more serious and/or persistent overactivity or agitation; frequent restlessness and/or wandering (e.g. day and night); significant problems with co-operation, largely resistant to help/assistance. Mild sexually disinhibited talk.
4 - At least one serious physical attack on others (over and above rating on 3); major and/or persistent destructive activity (e.g. fire-setting); persistent and serious threatening, behaviour; severe overactivity or agitation; sexually disinhibited or other inappropriate behaviour (e.g. deliberate inappropriate urination and/or defaecation); virtually constant restlessness and/or wandering, severe problems related to non-compliant/resistive behaviour.

2. Self directed injury.
- any self injurious behaviour which is not accidental, should be rated here; passive acts of self injurious behaviour, eg failing to take action to avoid a life threatening situation, are included here. In the case of accidental self injury any cognitive problem is rated at Scale 4 and the injury at Scale 5. Do not include illness or injury as a direct consequence of drug / alcohol use rated at Scale 3 (e.g. cirrhosis of the liver or injury resulting from drunk driving are rated at Scale 5).

0 - No problem of this kind during the period rated.
1 - Fleeting thoughts of self-harm or suicide but little or no risk during the period.
2 - Mild risk during period; includes more frequent thoughts or talking, about self harm or suicide (including 'passive' ideas of self-harm such as not taking avoiding action in a potentially life threatening situation e.g. whilst crossing a road).
3 - Moderate to serious risk of deliberate self-harm; includes frequent/persistent thoughts or talking about self-harm; includes preparatory behaviours, e.g. collecting tablets. Self injurious acts.
4 - Suicide attempt and/or serious self injurious acts during the period rated.

3. Problem drinking or drug use.
- do not include aggressive / destructive behaviour, rated at Scale 1. Do not include physical illness or disability, rated at Scale 5. Do not include accidental misuse of alcohol or drugs (prescribed or otherwise) e.g. in the context of dementia .

0 - No problem of this kind during the period rated.
1 - Some overindulgence but within social norm.
2 - Occasional loss of control of drinking or drug use, but not a serious problem.
3 - Marked craving or dependence on alcohol or drug use with frequent loss of control, drunkenness, etc.
4 - Major adverse consequences/incapacitated from alcohol/drug problems.

4. Cognitive problems.
- Rate any problems with orientation, attention, planning and organisation, memory, language or visuo-spatial function. Do not include temporary problems (e.g. hangovers) which are clearly associated with alcohol or other drug l medication use, rated at Scale 3.

0 - No problem of this kind during the period rated.
1 - Minor problems requiring no action (e.g. some difficulty with orientation in time; slightly distractible and slight problems with concentration; has difficulties prioritising tasks, attending to two things at once; a degree of forgetfulness but still able to actively learn new information; occasional errors in speech but do not disrupt meaning).
2 - Mild problems but definitely present (e.g. frequently disorientated in time; difficulty finding way in new or unfamiliar surroundings; has some difficulty concentrating, attention span is limited; difficulty organising complex tasks; definite problems learning new information such as names, recollection or recent events and the memory problems interfere with everyday activities; able to deal with simple verbal material but some difficulties with understanding, and/or expression of more complex language).
3 - Moderate problems (e.g. usually disorientated in time, often to place; has lost the way in a familiar place; attentional problems interfere with ability to think clearly; perseveration disrupts thinking at times; has difficulties organising everyday activities; new material rapidly lost, only highly learned material retained, occasional failure to recognise familiar individuals; expressive and/or receptive dysphasia).
4 - Severe problems (e.g. consistently disorientated in time and place; hardly capable of the simplest tasks eg. making a cup of tea; attentional problems disrupt thinking; severe perseveration; very poor memory, only fragments remain, loss of distant as well as recent information, hardly able to learn any new information, unable to recognise or to name close friends/relatives; no communication possible through language/inaccessible to speech).

5. Physical illness or disability problems.
- include illness or disability from any cause, including epilepsy, that limits mobility, impairs sight, hearing or conscious level or otherwise interferes with personal functioning (e.g. pain). Also include adverse effects of medication and effects of drug or alcohol use. Disability resulting from fatigue and hypersomnolence should be rated here.

0 - No significant physical health, disability or mobility problems during the period rated.
1 - Minor health problem during the period rated (e.g. cold); some impairment of sight and/or hearing (but still able to function effectively with the use of glasses and/or hearing aid).
2 - Physical health problem associated with mild restriction of activities and/or mobility (e.g. restricted walking distance, some degree of loss of independence), moderate impairment of sight and/or hearing (with functional impairment despite the appropriate use of glasses and/or hearing aid), some degree of risk of falling, but low and no episodes to date, problems associated with mild degree of pain.
3 - Physical health problem associated with moderate restriction of activities and/or mobility (e.g. requires an aid - stick, zimmer frame or wheelchair - for independent mobility, or requires occasional help with mobility); more severe impairment of sight and/or hearing (short of Rating 4); significant risk of falling, ± one or more falls; problems associated with a moderate degree of pain; slight impairment of conscious level.
4 - Major physical health problems associated with severe restriction of activities and/or mobility (e.g. chair or bed bound); severe impairment of sight and/or hearing (e.g. registered blind or deaf); high risk or falling, ± one or (usually) more falls because of physical illness or disability; problems associated with severe pain; **moderate / severe impaired level of consciousness**.

6. Problems associated with hallucinations or delusions or confabulations.

- include hallucinations or delusions or confabulations irrespective of diagnosis. Include odd or bizarre behaviour only if it can be attributed to hallucinations or delusions or confabulations (otherwise rate as scale 1). Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions or confabulations which are rated at Scale 1.

0 - No evidence of hallucinations or delusions or confabulations during the period rated.
1 - Somewhat odd or eccentric beliefs not in keeping, with cultural norms.
2 - Hallucinations (e.g. voices, visions) or delusions or confabulations are present, but there is little distress to patient or manifestation in bizarre behaviour, i.e. present but mild clinical problem.

3 - Marked preoccupation with hallucinations or delusions or confabulations, causing significant distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.
4 - Mental state and behaviour is seriously and adversely affected by hallucinations or delusions or confabulations, with a major impact on the patient and/or others, i.e. severe clinical problem.

7. Problems with depressive symptoms
- do not include overactivity or agitation, rated at Scale 1, Do not include suicidal ideation or attempts, rated at Scale 2. Do not include delusions or hallucinations, rated at Scale 6. Rate associated problems (e. changes in sleep, appetite or weight; anxiety symptoms) at Scale 8. Depressed mood should be rated regardless of whether it might appear to be an "understandable" reaction to disability, or an endogenous depression.

0 - No problems associated with depression during the period rated.
1 - Gloomy: or minor changes in mood only.
2 - Mild but definite depressive symptoms on subjective and/or objective measures (e.g. loss of interest and/or pleasure, lack of energy, loss of self-esteem, feelings of guilt).
3 - Moderate depressive symptoms on subjective and/or objective measures (depressive symptoms more marked).
4 - Severe depressive symptoms on subjective and/or objective grounds (e.g. profound loss of interest and/or pleasure, preoccupation with ideas of guilt or worthlessness).

8. Other mental and behavioural problems.
rate only the single most severe clinical problem not considered in Scales 6 and 7. Specify the type of problem by entering the appropriate letter. A phobic; B anxiety; C obsessive-compulsive; D stress; E dissociative; F somatoform; G eating; H sleep; I sexual; J other (specify).

0 - No evidence of any of these problems during period rated.
1 - Minor non-clinical problems.
2 - A problem is clinically present, but at a mild level e.g. the problem is intermittent, the patient maintains a degree of control and/or is not unduly distressed.
3 - Moderately severe clinical problem e.g. more frequent, more distressing or more marked symptoms.
4 - Severe persistent problem which dominates or seriously affects most activities.

9. Problems with relationships.
- problems associated with social relationships, identified by the patient and/or apparent to others / carers. Rate the patient's most severe problem associated with active or passive withdrawal from, or tendency to dominate, social relationships, and/or non-supportive, destructive or self-damaging relationships.

0 - No significant problems during the period.
1 - Minor non-clinical problem.
2 - Definite problems in making, sustaining or adapting to supportive relationships (e.g. because of controlling manner, or difficult, exploitative or abusive relationships with carers), definite difficulties reported by patient / others / carers, but mild.
3 - Persisting significant problems with relationships; moderately severe conflict or problems identified within the relationship by the patient and/or apparent to others/carers.
4 - Severe difficulties associated with social relationships (e.g. isolation, withdrawal, conflict, abuse); major tensions and stresses (e.g. threatening breakdown of relationship).

10. Problems with activities of daily living.
rate the overall level of functioning safely in activities of daily living (ADL): e.g. problems with basic activities of selfcare such as eating, washing, dressing, toilet,- also complex skills such as budgeting, recreation, use of transport. Include any ***lack of motivation*** *for using self-help opportunities, since this contributes to a lower overall level of functioning. Do not include lack of opportunity for exercising intact abilities and skills, rated at Scales 11 and 12.*

0 - No problems during the period rated; good ability to function effectively in all basic activities (e.g. continent - or able to manage incontinence appropriately, able to feed self and dress) and complex skills (e.g. driving or able to make use of transport facilities, able to handle financial affairs appropriately).
1 - Minor problems only without significantly adverse consequences; e.g. untidy, mildly disorganised, some evidence to suggest a decline from previous functional level (especially with regard to complex skills) but still able to cope effectively.
2 - Self care and basic activities adequate **though prompting may be required**, but difficulty with more complex skills (e.g. problems organising and making a drink/meal, deterioration in personal interests especially outside the home situation, problems with driving, transport or financial judgements).
3 - Problems evident in one or more areas of basic self-care activities (e.g. needs some supervision with dressing and eating, occasional urinary incontinence or continent only if toileted), inability to perform several complex skills in safety. Consistently requires **prompting** to perform activities.
4 - Severe disability or incapacity in all or nearly all areas of basic and complex skills, or lack of safety in any area (e.g. full supervision required with dressing and eating, frequent urinary ± faecal incontinence)

11. Problems with living conditions.

- rate overall severity of problems with the quality of living conditions / accommodation and daily domestic routine taking into account the patient's preferences and degree of satisfaction with their circumstances. Are the basic necessities met (heat, light, hygiene)? If so, does the physical environment contribute to maximising independence and minimising risk, and provide a choice of opportunities to facilitate the use of existing skills and the development of new ones? Do not rate the level of functional disability itself which is rated at Scale 10.

NB: Rate the patients usual accommodation. If in acute ward, rate the home accommodation. If in rehabilitation unit and close to discharge, rate confirmed discharge accommodation.

0 - Accommodation and living conditions are acceptable; helpful in

keeping any disability rated at Scale 10 to the lowest level possible and minimising any risk, and supportive of self-help, the patient is satisfied with their accommodation.
1 - Accommodation is reasonably acceptable with only minor or transient problems related primarily to the patients preferences rather than any significant problems or risks associated with their environment (e.g. not ideal location, not preferred option, doesn't like food).
2 - Basics are met but significant problems with one or more aspects of the accommodation and/or regime (e.g. lack of proper adaptation to optimise function relating, for instance to stairs, lifts or other problems or access); may be associated with risk to patient (e.g. of injury) which would be otherwise reduced.
3 - Distressing/multiple problems with accommodation; e.g. some basic necessities absent (e.g. unsatisfactory and/or unreliable heating, lack of proper cooking facilities, inadequate sanitation), clear elements of risk to the patient resulting from aspects of physical environment.
4 - Accommodation is unacceptable; e.g. lack of basic necessities, patient is at risk of eviction, or "roofless", or living conditions are otherwise intolerable making patient's problems worse and/or placing them at high risk of injury.

12. Problems with activities.

- rate the overall level of problems with the quality of the day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, lack of funding, lack of access to supportive facilities e.g. staffing and equipment of day centres, social clubs etc. Do not rate the level of functional disability itself, rated at Scale 10. Do not rate if the patient refuses to take part, or is too antisocial to take part, in activities which are nevertheless available, rated at appropriate scale.

NB: Rate the patient's usual situation. If in acute ward, rate activities during period before admission. If in rehabilitation unit and close to discharge, rate confirmed discharge arrangements.

0 - Patient's day-time environment is acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible and maximising autonomy.
1 - Minor or temporary problems e.g. good facilities available but not always at appropriate times for the patient.
2 - Limited choice of activities; e.g. insufficient carer or professional support; useful day setting available but for very limited hours.
3 - Marked deficiency in skilled services and support available to help optimise activity level and autonomy, little opportunity to use skills or to develop new ones; unskilled care difficult to access.
4 - Lack of any effective opportunity for day-time activities makes the patient's problems worse or patient refuses services offered which might improve their situation

Amended from **HoNOS 65+** by Simon Fleminger on behalf of the UK Psychiatrists Brain Injury Group June 1999

Comments
- in particular on any difficulties with the rating scale:-

HoNOS-*ABI* Score Sheet

Rate 9 if not known or Not applicable
Circle the score

1. Active Disturbance of Social Behaviour	0	1	2	3	4
2. Self directed injury	0	1	2	3	4
3. Problem Drinking or Drug use	0	1	2	3	4
4. Cognitive Problems	0	1	2	3	4
5. Physical illness or disability problems	0	1	2	3	4
6. Problems with hallucinations / delusions / confabulation	0	1	2	3	4
7. Problems with depressive symptoms	0	1	2	3	4
8. Other mental and behavioural problems	0	1	2	3	4
9. Problems with relationships	0	1	2	3	4
10. Problems with activities of daily living	0	1	2	3	4
11. Problems with living conditions	0	1	2	3	4
12. Problems with activities	0	1	2	3	4

Name of Patient ..

Name of Rater ..

Date of rating ..

Care and Needs Scale (CANS) – 25 May 2004

Date: **Name:** **Age:** **Date of Injury:** **MRN:**

INSTRUCTIONS: TICK ANY OF THE CARE AND SUPPORT NEEDS THAT APPLY (COLUMN 1), THEN CIRCLE THE NUMBER IN COLUMN 2 THAT CORRESPONDS TO LENGTH OF TIME THAT CAN BE LEFT ALONE (COLUMN 3)

Section 1: Type of care and support need	Hrs / week	Level	Section 2: Length of time that can be left alone
Group A: CANS Levels 8, 7, 6 or 5: Requires nursing care, surveillance for severe behavioural/cognitive disabilities, and/or assistance with very basic ADLs:		8	Cannot be left alone Needs nursing care, assistance and/or surveillance 24 hours per day
❑ tracheostomy management ❑ nasogastric/PEG feeding ❑ bed mobility (e.g., turning) ❑ wanders/gets lost ❑ exhibits behaviours that have the potential to cause harm to self or others ❑ has difficulty in communicating basic needs due to language impairments Physical/standby assistance or supervision for: ❑ continence ❑ feeding ❑ transfers/mobility (including stairs and indoor surfaces)	____ ____ ____ ____ ____ ____ ____ ____ ____	7 6 5	Can be left alone for a few hours Needs nursing care, assistance and/or surveillance 20-23 hours per day Can be left alone for part of the day, but not overnight Needs nursing care, assistance, supervision and/or direction 12-19 hours per day Can be left alone for part of the day and overnight Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills
Group B: CANS Level 5: Requires assistance, supervision, direction and/or cueing for basic ADLs: ❑ personal hygiene/toileting ❑ bathing/dressing ❑ simple food preparation	____ ____ ____	5	Can be left alone for part of the day and overnight Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills
Group C: CANS Levels 5, 4, 3 or 2: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation: ❑ shopping ❑ housework/home maintenance ❑ medication use ❑ money management ❑ everyday devices (e.g., telephone, television) ❑ transport and outdoor surfaces ❑ parenting skills ❑ interpersonal relationships ❑ leisure and recreation/play ❑ employment/school	____ ____ ____ ____ ____ ____ ____ ____ ____ ____	5 4 3 2	Can be left alone for part of the day and overnight Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills Can be left alone for a few days a week Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week Can be left alone for almost all week Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support
Group D: CANS Levels 4, 3 or 2: Requires supports: ❑ informational supports (e.g., advice) ❑ emotional supports	____ ____	4 3 2	Can be left alone for a few days a week Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week Can be left alone for almost all week Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support
Group E: CANS Level 1: Fully independent: ○ Lives fully independently, with or without physical or other aids (e.g., hand rails, diary notebooks), and allowing for the usual kinds of informational and emotional supports the average person uses in everyday living		1	Can live in the community, totally independently Does not need contact

SYDNEY PSYCHOSOCIAL REINTEGRATION SCALE - 2 (SPRS-2)
FORM B (CLINICIAN/RELATIVE)

ROBYN TATE

DEVELOPED IN ASSOCIATION WITH
ADELINE HODGKINSON, AHAMED VEERABANGSA, ANNE PFAFF AND GRAHAME SIMPSON
BRAIN INJURY REHABILITATION UNIT, LIVERPOOL HOSPITAL, SYDNEY

Name:	**Sex: _ / _**	**ID**
Date: / /	**Date of injury: / /**	**DoB: / /**
Cause of injury:	**Duration of coma:**	**Duration of PTA**

BACKGROUND INTERVIEW

1. What is the person's current occupation?:

2. What are his/her work duties at present?:

3. What was his/her job at the time of the injury?:

4. What were his/her work duties in that job?:

5. How many jobs has he/she had since the injury (not including work trials or voluntary work)?:

6. What are/were his/her leisure interests, recreation, hobbies, and club membership, at present and at time of injury?:

6A. AT TIME OF INJURY **6B. AT PRESENT**

7. What is/was his/her weekly program of work, leisure/recreational activities at present and at time of injury?:

7A. AT TIME OF INJURY **7B. AT PRESENT**

8. a) What is his/her marital status at present?:
   b) What was it at the time of the injury?:
9. a) Who is in his/her circle of close friends at present?:

   b) Who was in his/her circle of close friends at the time of the injury?:

10. a) Who does he/she live with at present?:
    b) Who did he/she live with at the time of the injury?:

WORK AND LEISURE

1. Current work: HOW DO YOU RATE WORK (OR STUDY), OR THE TYPE OF WORK (STUDY)?
(If a student, answer the question in this section in terms of changes in studies)

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	Works (studies) less than average hours per week, OR work duties (studies) are easy/light ones.....	**3**
❑ **Definite difficulty:**	Works casually, OR has some help from others in doing some work (study)	**2**
❑ **A lot of difficulty:**	Unemployed, OR in rehabilitation, OR in a supported work program, OR do volunteer work, OR receives remedial assistance in studies ……	**1**
❑ **Very poor:**	Unable to work (study) at present …….....	**0**

2. Work skills: HOW DO YOU RATE WORK (STUDY) SKILLS?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	For example, has to put in a lot of effort to get good results, gets tired easily, loses concentration ……	**3**
❑ **Definite difficulty:**	For example, sometimes makes mistakes.....……	**2**
❑ **A lot of difficulty:**	For example**,** he or she is slow, work is of poor quality .....……..	**1**
❑ **Very poor:**	For example, needs constant supervision and/or reminders ……..……..	**0**

3. Leisure: HOW DO YOU RATE THE NUMBER OR TYPE OF LEISURE ACTIVITIES OR INTERESTS?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	Has leisure activities and interests, but does not do them often …….. ……	**3**
❑ **Definite difficulty:**	Definite difficulties in developing and doing leisure activities and interests …….	**2**
❑ **A lot of difficulty:**	A lot of difficulty developing and doing leisure activities and interests ……	**1**
❑ **Very poor:**	Does not have any leisure activities or interests at present .....….....	**0**

4. Organising activities: HOW DO YOU RATE THE WAY HE/SHE ORGANISE S WORK AND LEISURE ACTIVITIES?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	For example, needs prompts or supports from others…….….....	**3**
❑ **Definite difficulty:**	Fairly dependent on other people to organise activities, e.g. others suggest what to do and how to go about it……..……	**2**
❑ **A lot of difficulty:**	Needs other people to do the organising, e.g. making arrangements, providing transport……	**1**
❑ **Very poor:**	Dependent on other people to suggest and organise activities at present.....	**0**

RELATIONSHIPS

5. Spouse or partner: DOES HE/SHE HAVE A PARTNER OR SPOUSE?
a) IF YES, HOW DO YOU RATE THE RELATIONSHIP?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	Not good, but still able to get along together, and if it broke down has the skills to form new relationship ……	**3**
❑ **Definite difficulty:**	Definite difficulties, but has the skills to form and also probably maintain a new relationship ……..……	**2**
❑ **A lot of difficulty:**	Might have the skills to form a new relationship.....…….	**1**
❑ **Very poor:**	Relationship is extremely limited (e.g., partner is a primary caretaker) and does not have the skills to form a new relationship……	**0**

b) IF NO, HOW DO YOU RATE THE ABILITY TO FORM AND MAINTAIN SUCH A RELATIONSHIP?

❑ **Very good**	……	**4**
❑ **A little difficulty:**	Has the skills to form and maintain a new relationship ……	**3**
❑ **Definite difficulty:**	Has the skills to form and also probably maintain a new relationship……..…	**2**
❑ **A lot of difficulty:**	Might have the skills to form a new relationship……	**1**
❑ **Very poor:**	Does not have the skills to form a new relationship…….…….	**0**

6. Family: HOW DO YOU RATE THE RELATIONSHIPS WITH OTHER FAMILY MEMBERS?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	Not good, but still able to get along together ……..……	**3**
❑ **Definite difficulty:**	Definite difficulties, but still sees family ……	**2**
❑ **A lot of difficulty:**	A lot of difficulties getting along with some family members ….....……	**1**
❑ **Very poor:**	Relationship is extremely limited and there has been breakdown ……	**0**

]

7. Friends and other people: HOW DO YOU RATE THE RELATIONSHIPS WITH OTHER PEOPLE OUTSIDE FAMILY (SUCH AS CLOSE FRIENDS, WORK MATES, NEIGHBOURS)?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	Not good, but has close friends, makes new friends, and gets along with work mates and neighbours ……	**3**
❑ **Definite difficulty:**	Definite difficulties, but still sees some friends once a month or more and can make new friends ……	**2**
❑ **A lot of difficulty:**	Only sees a few friends (or other people outside family), and does not make new friends easily ……....	**1**
❑ **Very poor:**	Does not see any friends (or other people outside the family)……	**0**

8. Communication: HOW DO YOU RATE THE COMMUNICATION SKILLS (THAT IS, TALK WITH OTHER PEOPLE AND UNDERSTAND WHAT OTHERS SAY)?

❑ **Very good:**	……..	**4**
❑ **A little difficulty:**	For example, rambles and get off the point, talk is sometimes inappropriate, has some trouble finding the words to express himself/herself……..……	**3**
❑ **Definite difficulty:**	For example, difficulties thinking of things to say, joining in talk with groups of people, only talks about himself/herself ……...……	**2**
❑ **A lot of difficulty:**	For example, has trouble understanding what people say……...	**1**
❑ **Very poor:**	Communication is almost impossible.....…….....	**0**

LIVING SKILLS

9. Social Skills: HOW DO YOU RATE THE SOCIAL SKILLS AND BEHAVIOUR IN PUBLIC?

❑ **Very good:**	……	**4**
❑ **A little difficulty:**	For example, is awkward with other people, does not worry about what other people think or want ……	**3**
❑ **Definite difficulty:**	For example, can act in a silly way, is not as tactful or sensitive to other people's needs……	**2**
❑ **A lot of difficulty:**	For example, is dependent on other people, is socially withdrawn, has difficulty interacting appropriately with other people ……..	**1**
❑ **Very poor:**	For example, has temper outbursts in public, requires supervision when with other people ……..	**0**

10. Personal habits: HOW DO YOU RATE THE PERSONAL HABITS (E.G. HIS/HER CARE IN CLEANLINESS, DRESSING AND TIDINESS)?

❑ **Very good:**	……	**4**
❑ **A little difficulty:**	For example, does not take much care …….....	**3**
❑ **Definite difficulty:**	Attends to own hygiene, dress and tidiness, but has definite difficulties in this area; needs supervision …….	**2**
❑ **A lot of difficulty:**	Needs prompts, reminders or advice from others, but responds to these; needs stand-by assistance ...…….……	**1**
❑ **Very poor:**	Needs prompts, reminders or advice from others, but is unwilling to respond to these; needs hands-on assistance …….…….....	**0**

11. Community travel: HOW DO YOU RATE THE USE OF TRANSPORT AND TRAVEL AROUND THE COMMUNITY?

NOTE: Do not include the driver of transport, or other passengers using such transport, in rating whether a person can travel "on his/her own".

❑ **Very good:**	……	**4**
❑ **A little difficulty:**	Unable to use some forms of transport (e.g. driving a car) but can still get around in the community by using other forms of transport without help……	**3**
❑ **Definite difficulty:**	Definite difficulty using transport, but after training can travel around the community on his/her own ……	**2**
❑ **A lot of difficulty:**	Needs assistance to plan use of transport, but with such help can travel around the community on his/her own ……..…….	**1**
❑ **Very poor:**	Is unable to go out into the community on his/her own	**0**

12. Accommodation: HOW DO YOU RATE THE LIVING SITUATION?

❑ **Very good:**	……	**4**
❑ **A little difficulty:**	Lives in the community, but with emotional or social supports provided by other people, such as family, friends or neighbours. Could not be left alone without supports for a two-week period……	**3**
❑ **Definite difficulty:**	Lives in the community, but could not be left alone for a weekend unless someone checked that everything was OK ……	**2**
❑ **A lot of difficulty:**	Lives in the community but in supported accommodation, such as a group home, boarding house, transitional living unit, in family home but requires daily supervision or assistance …….	**1**
❑ **Very poor:**	Needs care, which may be at home requiring extensive, daily supervision or other care OR in a facility, e.g., a nursing home, residential service, rehabilitation unit ……	**0**

APPENDIX B

SEMI STRUCTURED INTERVIEW QUESTIONS

1. What were the main issues at the time of referral to the community team?
2. What were the goals the team were working on with the person?
3. What were the types of challenging behaviours the team encountered?
4. Were the challenging behaviours present initially?
   If not, at what point post-injury did they start to become apparent?
5. In which environments did the behaviours occur?
6. What sorts of consequences or problems were the behaviours causing?
7. How did the team respond – what sorts of strategies/approaches were used?
8. Were there difficulties in implementing the management approaches?
9. Were the interventions useful – what sorts of approaches seemed to work?
10. What have been the outcomes? What is the person doing now?
11. What was the most challenging aspect of the case?
12. What would have helped in making it easier?
13. Was there any evidence of pre-morbid behavioural problems or mental health/substance abuse issues?
14. Were there concurrent rehabilitation issues (physical, medical, functional, psychosocial)?
    To what extent did the challenging behaviours interfere or complicate the management of these other issues?

APPENDIX C

CLIENT DEMOGRAPHIC CHARACTERISTICS

Table C.1: Demographics of BIRP clients

Demographic variables	n	%
Gender		
Female	156	23.7
Male	503	76.3
Region of birth		
Australia/New Zealand	522	79.2
Europe (incl. UK and Ireland)	24	3.6
Americas	10	1.6
Pacific Islands	9	1.4
Africa	7	1.1
Middle East	39	5.9
Asia	38	5.8
Unknown	10	1.5
Preferred language		
English	591	89.7
Other Non-English	59	11.7
Unknown	9	1.4
Indigenous status		
Non-indigenous	590	89.5
Indigenous	22	3.4
Unknown	47	7.2
Geographic location		
Urban	405	61.5
Regional	199	30.2
Remote	44	6.7

Table C.2: Injury-related characteristics of all clients

Injury variables	n	%
Age at injury		
zero to 14 years	40	6.1
15 to 24 years	212	32.2
25 to 34 years	126	19.1
35 to 44 years	120	18.2
45 to 54 years	105	15.9
55 to 64 years	45	6.8
Unknown	11	1.7
PTA duration		
24 hours or less	26	4.0
2-6 days	71	10.8
1-4 weeks	170	25.8
1-6 months	232	35.2
Greater than six months	42	6.4
Unknown	118	17.9
Severity of Injury		
Mild to Moderate	36	5.5
Severe	544	82.5
Unknown	79	12.0
Injury circumstance		
MVA driver	139	21.1
MVA passenger	84	12.7
MVA pedestrian	87	13.2
MVA bicycle/rollerblade/scooter/skateboard	10	1.5
MVA unspecified	7	1.1
MBA	64	9.7
Assault	97	14.7
Fall	100	15.2
Sport/leisure	34	5.2
Other traumatic brain injury	35	5.3
TBI but circumstance unknown	2	0.3

NB: To minimise missing PTA data a binomial Severity of Injury variable was created (mild to moderate versus severe injuries) based on Glasgow ComaScale (GCS) scores (at the scene or on acute admission) or medical record information (such as CT scan results, duration of coma or level of neurological impairment). Thirty-seven clients sustained their injuries by other traumatic means and for nine of these cases injury details were available: five had an object collide with head, two were injured by boat propellers, one was due to a gas cylinder explosion and one was hit by a train.

CLIENT INJURY CHARACTERISTICS

The median time for clients included in the study after their injuries was 2.21 years. The clinical injury characteristics of all clients included in the study are displayed in Table C.2. The data show that:

- Age of injury profile was typical for the TBI population, with peak incidence occurring in the 15-24 age group
- The sample was skewed toward the severe end of the TBI spectrum
- Motor vehicle accidents accounted for 59.3% of injuries

ADDITIONAL CLINICAL CHARACTERISTICS ABOUT CLIENTS

The clinical informants in the study completed questionnaires about client's pre-morbid characteristics, level of disability, care needs, participation and health outcomes. These characteristics are detailed below.

Pre-morbid alcohol and psychiatric history

Clinical informants rated the prevalence of pre-morbid conditions, finding that:

- 164 (24.9%) of clients had a significant history of alcohol abuse
- 93(14.1%) of clients had a significant clinical history of psychiatric disturbance.

Disability, care needs and psychosocial participation

The levels of disability (Disability Rating Scale, DRS), care needs (Care and Needs Scale, CANS) and participation (Sydney Psychosocial Reintegration Scale, SPRS) are displayed in Table C.3. Generally, disability and care needs were positively skewed, indicating a greater proportion of clients at lower levels of disability and having fewer care needs. In contrast, over 80% of clients showed poor or substantially limited levels of psychosocial participation.

Table C.3: Disability, care needs and participation of clients

	n	%
Disability Rating Scale		
No disability	82	12.6
Mild disability	120	18.4
Partial disability	191	29.3
Moderate disability	186	28.5
Moderate to severe disability	57	8.7
Severe disability	6	0.9
Extremely severe disability	10	1.5
Care and Needs Scale		
Independent	126	19.1
Intermittent contact	127	19.3
Weekly contact	92	14.0
Contact every few days	95	14.4
Up to 11 hours contact per day	113	17.1
12 to 19 hours contact per day	40	6.1
20 to 23 hours contact per day	26	3.9
24 hours contact per day	40	6.1
Sydney Psychosocial Reintegration Scale		
Poor reintegration	203	30.8
Substantially limited reintegration	345	52.4
Good reintegration	111	16.8

Health issues

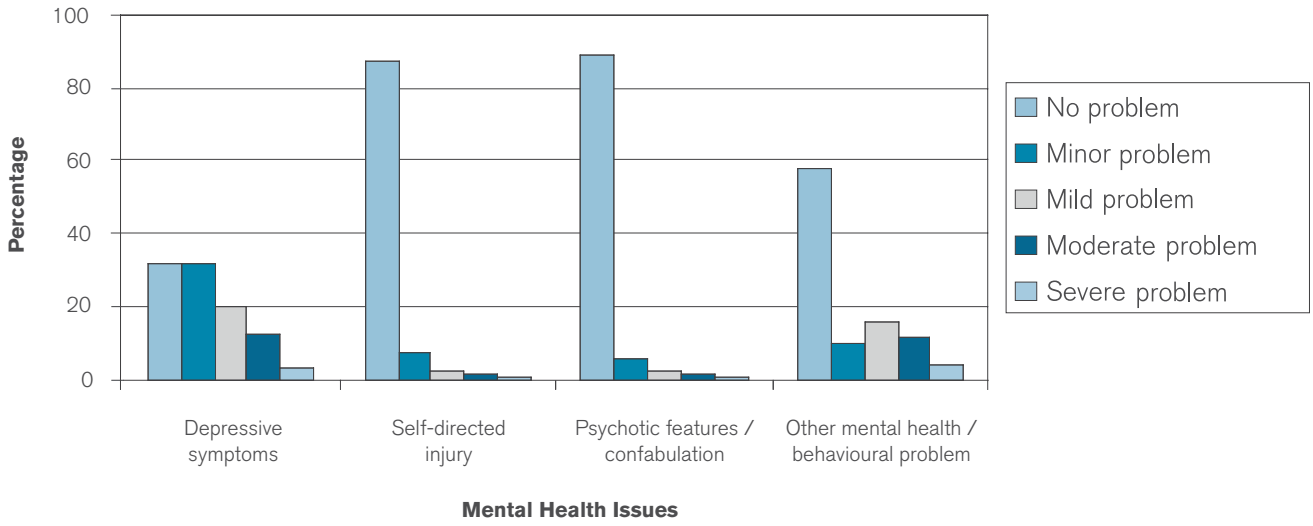
Co-morbidities and health-related issues were measured on the Health of the Nation Outcome Scale for Acquired Brain Injury (HoNOS-ABI). For the sample as a whole, the mean HoNOS-ABI score was 11.5 (SD=7.0), consistent with minor problems requiring no action. Information is presented below for more specific items on the HoNOS-ABI including mental health, drug and alcohol, cognitive and accommodation problems.

Drug and alcohol problems

Clinician ratings on the HoNOS-ABI drug and alcohol item revealed that:

- 459 (69.7%) had no problems with drugs or alcohol
- 72 (10.9%) had a minor problem
- 54 (8.2%) had a mild problem
- 48 (7.3%) had a moderate problem
- 26 (3.9%) had a severe problem

Figure C.1: Mental Health Issues.



Mental health problems

Rates of mental health problems encountered in the current client sample are displayed in Figure C.1. Four types of mental health problems were documented by the HoNOS-ABI, namely depressive symptoms, self-directed injury, psychotic features (hallucinations and delusions)/confabulations, and other mental health/behavioural problems. Overall, the findings were that:

- Depressive symptoms were most frequent
- Rates for self-directed injury and psychotic features were low
- Other mental health problems documented included:

– Anxiety (n=135, 20.5%)
– Stress (n=48, 7.3%)
– Phobia (n=9, 1.4%)
– Obsessive-compulsive signs (n=16, 2.4%)
– Dissociation (n=1, 0.2%)
– Eating disorders (n= 4, 0.6%)
– Sleep-related problems (n= 15, 2.3%)
– Sexual problems (n= 10, 1.5%)
– Unspecified problems (n=18, 2.7%)

Moderate and severe drug and alcohol problems reflected clinical indicators such as marked craving or dependence on alcohol or drugs, frequent loss of control and major adverse consequences.

Cognitive problems

Not surprisingly, cognitive problems were widespread across the sample:

- 62 (9.4%) had no cognitive problems
- 244 (37.0%) had a minor cognitive problem
- 216 (32.8%) had a mild cognitive problem
- 105 (15.9%) had a moderate problem
- 32 (4.9%) had severe cognitive problems

Moderate and severe cognitive problems reflected clinical indicators such as problems with attention, perseveration, organisation, new learning, the presence of dysphasia (receptive or expressive), and disorientation with respect of time.

Accommodation and living conditions problems

The profile of accommodation and living conditions indicated that only a small proportion of clients (4.5%, n=30) were having moderate to severe problems:

- 450 (68.3%) had no problems in this area
- 135 (20.5%) had a minor problem
- 44 (6.7%) had a mild problem
- 18 (2.7%) had a moderate problem
- 12 (1.8%) had a severe problem

Moderate to severe accommodation and living conditions problems reflected indicators such as inadequate sanitation, lack of cooking facilities, lack of basic necessities, or client at risk of eviction.

PSYCHOSOCIAL FACTORS "AT-RISK" OF BREAKING DOWN OVER THE COMING THREE MONTHS

Clinical informants also rated the likelihood of significant problems arising across seven psychosocial domains over the coming three months (see Table C.4).

Breakdown in family relationships was thought to be the most likely to occur, followed by a breakdown in health, employment and then accommodation. Only 25% of the sample was thought not at risk for any psychosocial breakdown. The median number of factors to breakdown for clients was 1.0 (25th percentile=0.0; 75th percentile=3.0).

Service-related characteristics of clients

The clinical informants also provided information about the services each client received from BIRP and from additional (non-BIRP) service providers.

BIRP SERVICES

BIRP staff providing services to clients

Data were collected on the number of BIRP staff involved with clients across the network. Staff most commonly involved with clients were case managers and rehabilitation physicians (68% and 64% respectively) followed by occupational therapists. The mean number of staff involved with clients was 3.3 (SD=2.0). See Figure C.2.

Table C.4: Future psychosocial breakdown risk of clients

	n	%
Family breakdown	269	40.8
Accommodation	190	28.8
Health	216	32.8
Education	48	7.3
Employment	214	32.5
Legal	82	12.4
Loss of program/service	94	14.3
No breakdown	170	25.8

Services provided by clinical informants to clients

The most common service provided by clinical respondents to BIRP clients was case management, received by three-quarters of clients, followed by assessment, received by just over half of the clients. Three clinicians did not indicate the service/s they provided. The mean number of services provided by clinical informants to clients was 2.9 (SD=1.8). See Figure C.3.

Clinical informants' perceptions of stress and complexity of clients they service

Clinical informants rated the degree of stress they experienced in working with their clients and how complex they viewed their clients (see Table C.5). As can be seen stress levels were positively skewed. Both stress and complexity were strongly correlated (spearman-rank r=0.7, p<0.05).

Figure C.2: BIRP services received by clients

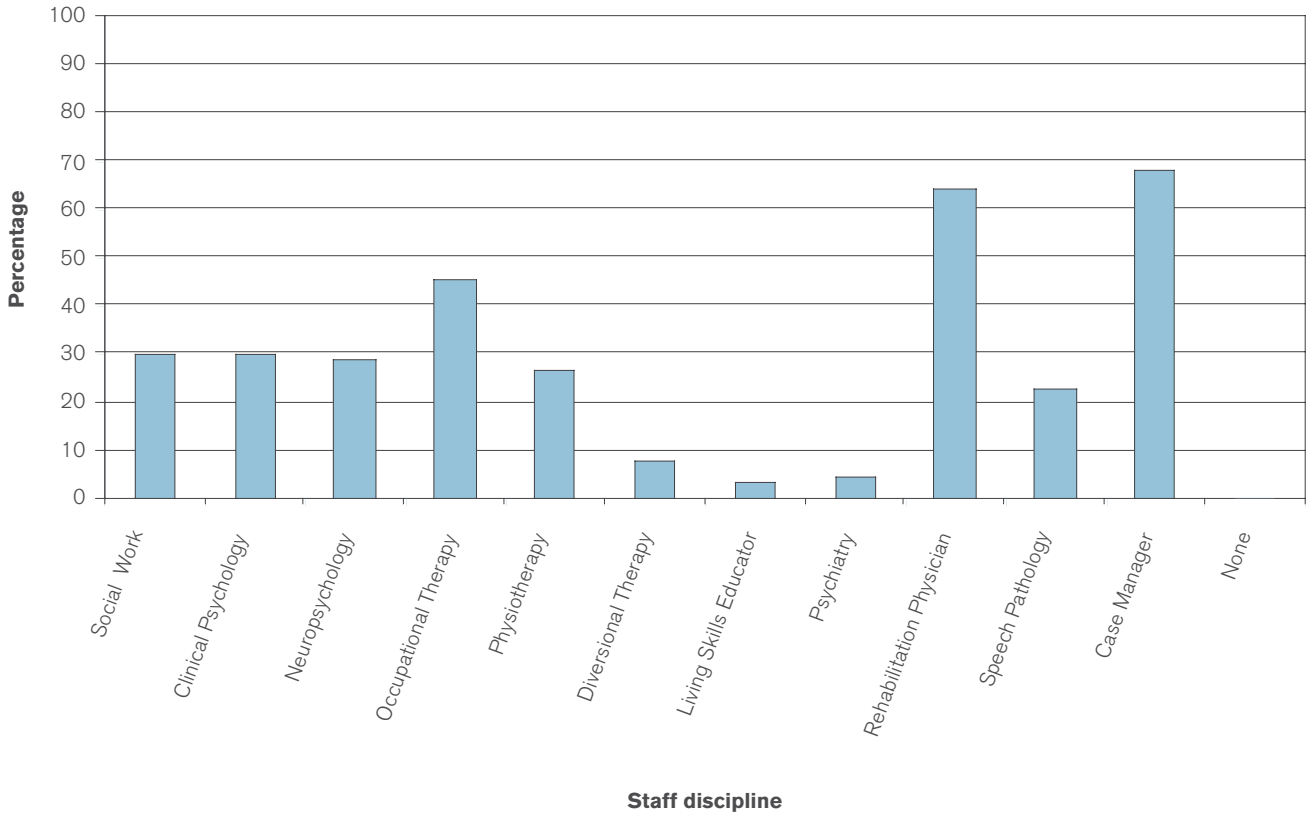


Figure C.3: Services provided by clinical informants to clients.

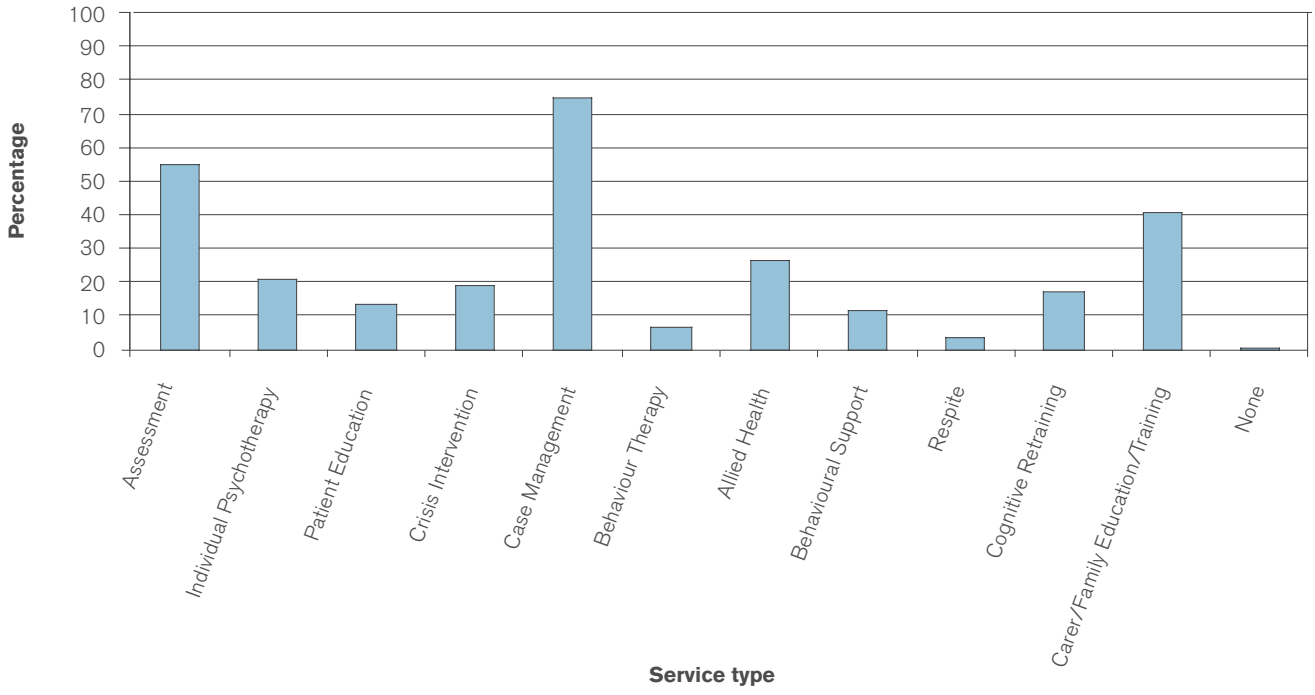
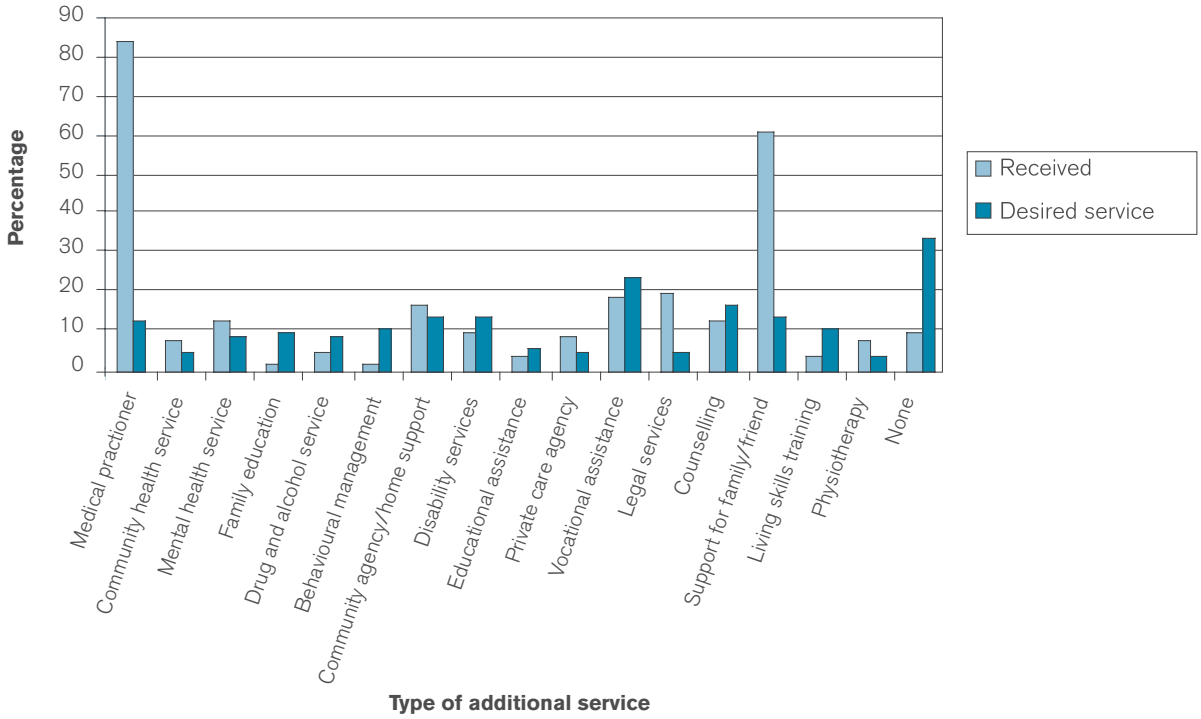


Figure C.4: Non-BIRP services accessed/received by clients or desired for them.



ADDITIONAL (NON-BIRP) SERVICES

The proportion of clients receiving additional services outside of the BIRP network was also documented (see Figure C.4). A diverse range of services was documented. The most common type of non-BIRP services accessed by clients was general practitioners/other medical specialists.

This was followed by informal (non-paid) support provided by family and friends. The mean number of additional services received by clients was 2.8 (SD=1.4). As a measure of unmet need, clinicians also identified additional services that were required but had not been accessed or received by the client.

Table C.5 Ratings of stress and complexity when working with clients

	n	%
Stress		
-0 no stress	155	23.5
-1	178	27.0
-2	119	18.1
-3 moderate stress	112	17.0
-4	54	8.2
-5	25	3.8
-6 severe stress	16	2.4
Complexity		
-0 no complexity	100	15.2
-1 minor complexity	209	31.7
-2 moderate complexity	205	31.1
-3 substantial complexity	111	16.8
-4 extreme complexity	34	5.2

APPENDIX D

RELATIONSHIP BETWEEN DIFFERENT CHALLENGING BEHAVIOURS AND PROBLEMS ASSESSED ON HoNOS-ABI

Table D.1 shows the proportion of clients with challenging behaviour at each level of severity for accommodation problems as measured using the HoNOS-ABI.

Table D.1: Percentage (%) of different types of challenging behaviour by severity of problems with accommodation/living conditions

	No problem	Minor problem	Mild problem	Moderate problem	Severe problem
VA*	19.3	39.3	47.4	33.3	50.0
PAO	4.9	12.6	13.6	5.6	25.0
PAS	4.0	6.7	6.8	11.1	0.0
PAP*	7.3	13.3	15.9	38.9	33.3
ISB*	1.8	7.4	6.8	5.6	8.3
PR*	9.6	19.3	18.2	5.6	50.0
WA	1.3	5.9	6.8	0.0	16.7
ISOC*	21.6	48.9	47.7	55.6	50.0
ADL*	17.1	28.1	27.3	61.1	91.7

Note. *$p<0.05$.

VA=Verbal aggressive behaviour; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseveration/ repetitive behaviour; WA=Wandering/absconding; ISOC=Inappropriate social behaviour; ADL=Adynamia/lack of initiation.

TABLE D.2 REPORTS THE CHI-SQUARED STATISTIC FOR EACH RELATIONSHIP DEPICTED IN TABLE D.1 AND THE CORRESPONDING P-VALUE.

The statistic was calculated with four degrees of freedom for each analysis. The table also shows the number and percentage of cells where the expected cell count in calculating the statistic was less than five.

Table D.2: Chi-square, p-value and number (percentage) of cells with expected cell count (ECC) less than five for relationship between mental health issues and individual challenging behaviours

	X^2	P	Low ECC
VA	37.37	.000	2 (20)
PAO	17.39	.001	3 (30)
PAS	4.18	.164	3 (30)
PAP	29.49	.000	3 (30)
ISB	12.58	.008	4 (40)
PR	26.25	.000	2 (20)
WA	19.43	.003	4 (40)
ISOC	52.30	.000	1 (10)
ADL	58.64	.000	2 (20)

TABLE D.3 REPORTS THE CHI-SQUARED STATISTIC FOR EACH RELATIONSHIP DEPICTED IN THE FIGURES AND THE CORRESPONDING P-VALUE.

The chi-squared statistic was calculated with four degrees of freedom for each analysis. The table also shows the number and percentage of cells where the expected cell count in calculating the chi-square statistic was less than five.

Table D.3: Chi-square, p-value and number (percentage) of cells with expected cell count (ECC) less than five for relationship between mental health issues and individual challenging behaviours

	X^2	P	Low ECC
In relation to depressive symptoms			
VA	29.82	.000	0 (0)
PAO	8.25	.083	1 (10)
PAS	48.76	.000	2 (20)
PAP	4.19	.381	1 (10)
ISB	3.76	.437	3 (30)
PR	5.88	.209	1 (10)
WA	2.41	.661	3 (30)
ISOC	6.08	.193	0 (0)
ADL	9.84	.043	0 (0)
In relation to self-directed injury			
VA	12.09	.017	4 (40)
PAO	21.32	.000	4 (40)
PAS	201.93	.000	4 (40)
PAP	12.40	.015	3 (30)
ISB	6.11	.191	4 (40)
PR	4.48	.345	3 (30)
WA	6.92	.140	4 (40)
ISOC	5.38	.250	4 (40)
ADL	4.37	.359	4 (40)

Table D.3 Continued: Chi-square, p-value and number (percentage) of cells with expected cell count (ECC) less than five for relationship between mental health issues and individual challenging behaviours

	X^2	P	Low ECC
In relation to psychotic features/confabulation			
VA	23.71	.000	4 (40)
PAO	20.45	.000	5 (50)
PAS	1.73	.785	5 (50)
PAP	20.25	.000	5 (50)
ISB	17.23	.002	5 (50)
PR	43.12	.000	5 (50)
WA	9.34	.053	5 (50)
ISOC	28.33	.000	3 (30)
ADL	14.07	.007	4 (40)
In relation to other mental/behavioural problems			
VA	29.74	.000	0 (0)
PAO	15.41	.004	2 (20)
PAS	22.71	.000	3 (30)
PAP	13.46	.009	1 (10)
ISB	15.43	.004	4 (40)
PR	10.40	.034	1 (10)
WA	5.84	.212	4 (40)
ISOC	23.02	.000	0 (0)
ADL	4.26	.372	0 (0)

VA=Verbal aggression; PAO=Physical aggression against objects; PAS=Physical aggression against self; PAP=Physical aggression against other people; ISB=Inappropriate sexual behaviour; PR=Perseverative/repetitive behaviour; WA=Wandering/absconding behaviour; ISOC=Inappropriate social behaviour; ADL=Adynamia/lack of initiation

RELATIONSHIP BETWEEN DIFFERENT CHALLENGING BEHAVIOURS AND SPECIFIC MENTAL HEALTH ISSUES ASSESSED ON HONOS-ABI

Figures D.1 to D.4 shows the proportion of clients with challenging behaviour at each level of severity of the different mental health items of the HoNOS-ABI. Figures D.1, D.2, D.3 and D.4 relate to severity of depressive symptoms, self-directed injury, psychotic features/confabulation and other mental/behavioural problems, respectively.

Figure D.1: Percentage of clients with different types of challenging behaviour at each level of severity of depressive symptoms.

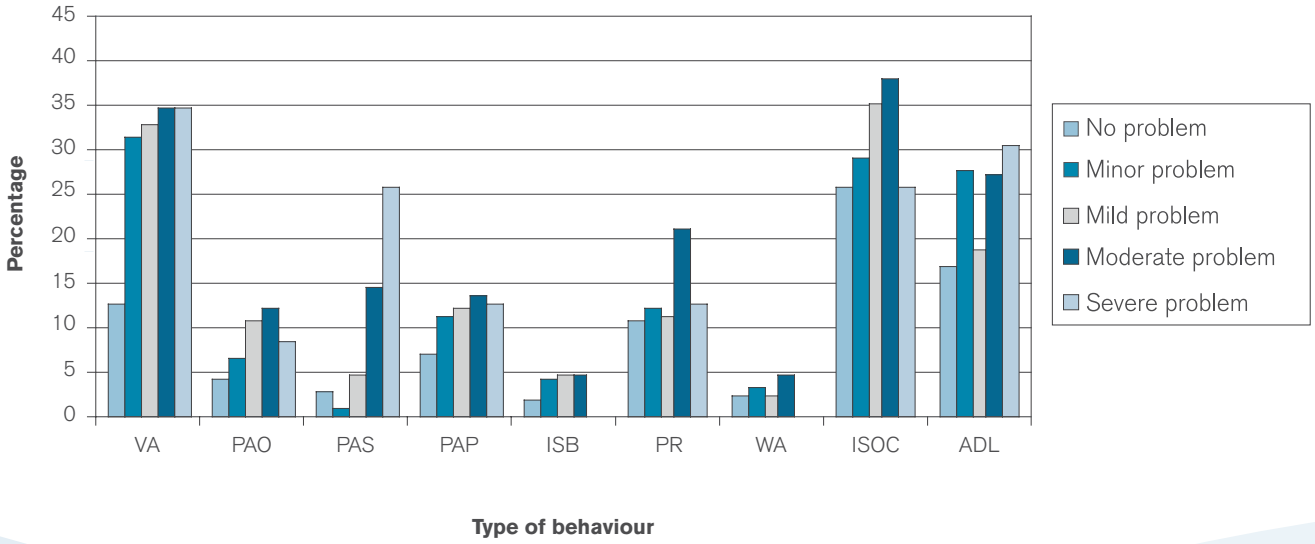


Figure D.2: Percentage of clients with different types of challenging behaviour at each level of severity of self-directed injury.

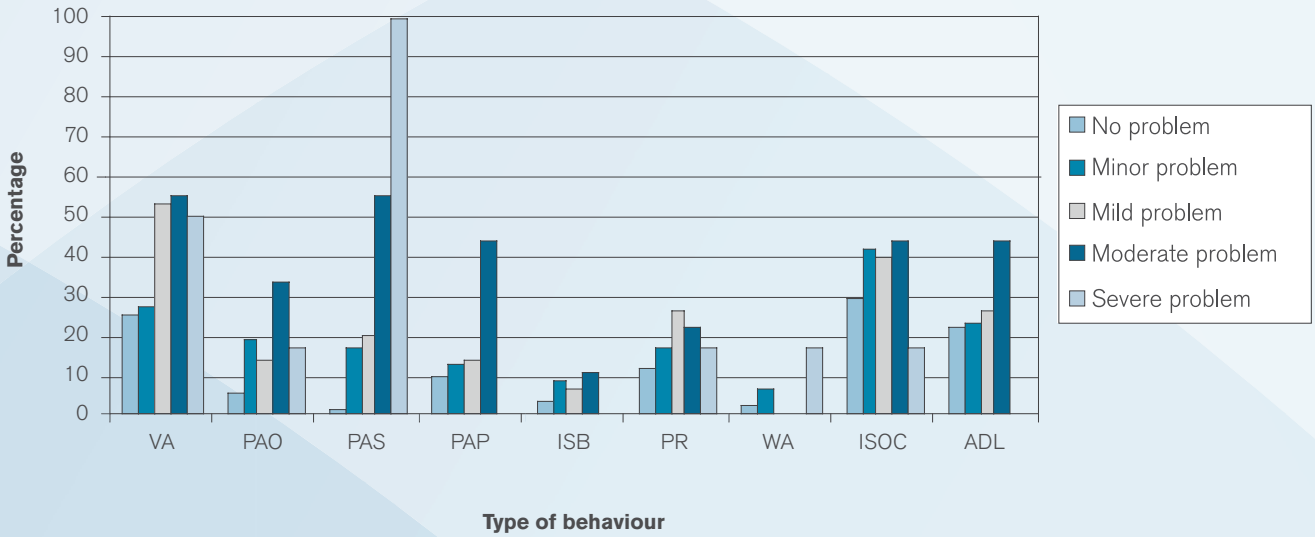


Figure D.3: Percentage of clients with different types of challenging behaviour at each level of severity of psychotic features/confabulation.

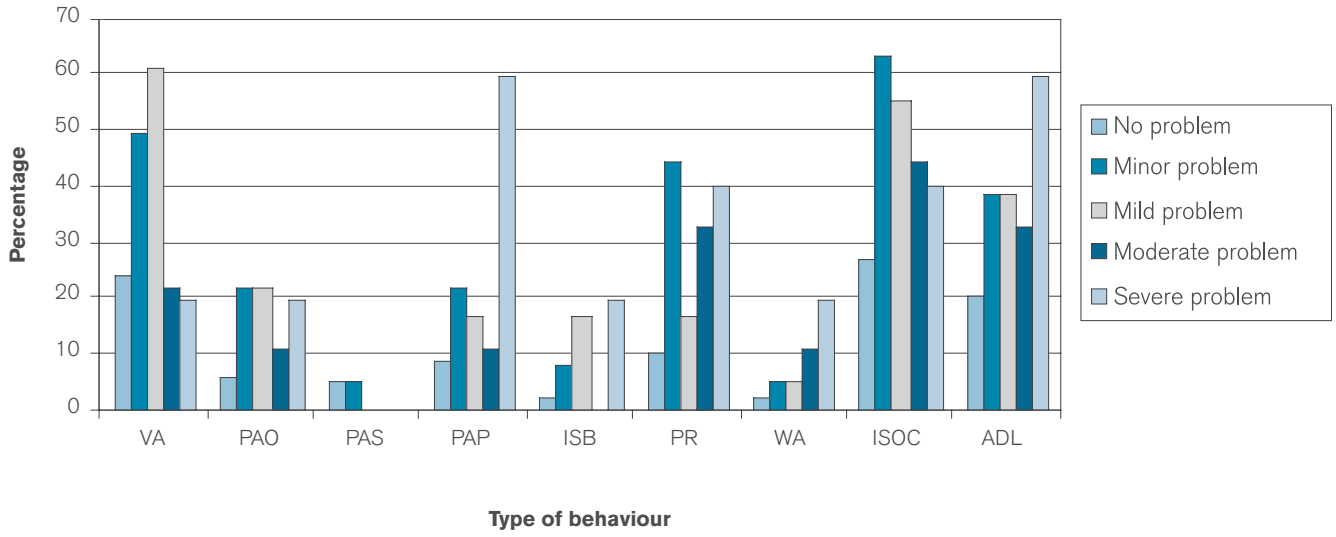
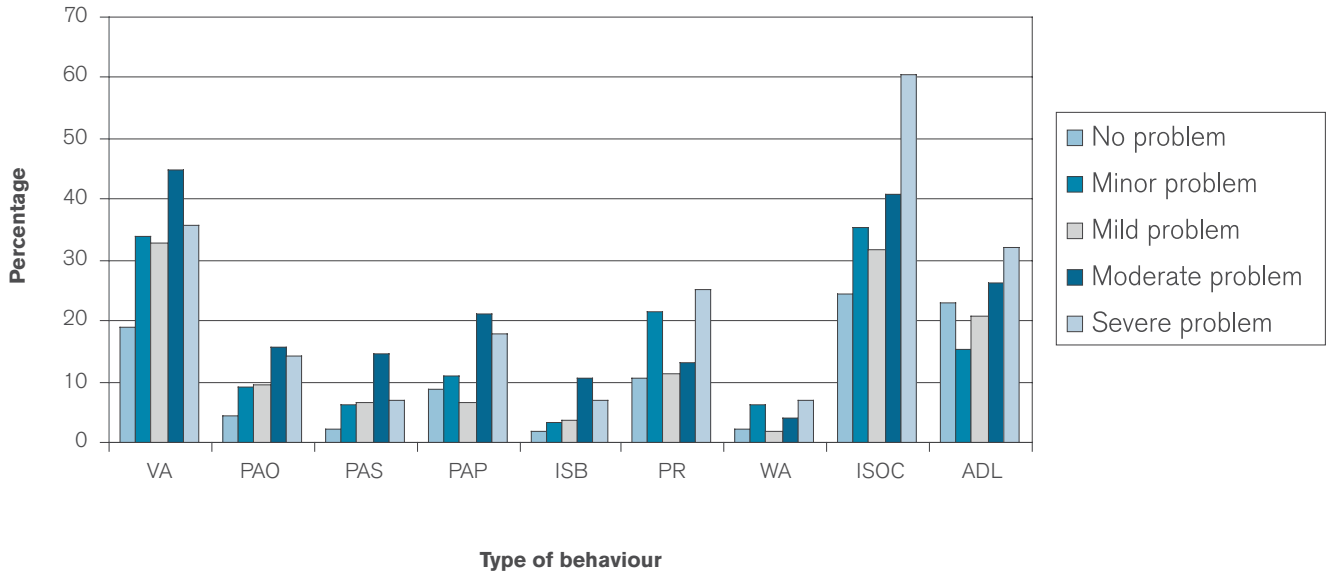


Figure D.4: Percentage of clients with different types of challenging behaviour at each level of severity of other mental/behavioural problems.



APPENDIX E

Table E.1: Final binary logistic regression model for absence/presence of challenging behaviour

	B	P	Odds ratio
No pre-injury alcohol problem			
Pre-injury alcohol problem	0.72	.004	2.05
No drug/alcohol problems			
Minor/mild drug/alcohol problems	0.67	.009	1.95
Moderate/severe drug/alcohol problems	1.39	.000	3.99
No cognitive problems			
Minor cognitive problems	0.50	.227	1.64
Mild cognitive problems	1.21	.004	3.35
Moderate to severe cognitive problems	1.51	.002	4.54
No depressive symptoms			
Minor depressive symptoms	0.70	.004	2.01
Mild depressive symptoms	0.69	.015	1.99
Moderate to severe depressive symptoms	0.94	.004	2.55
No other mental/behavioural problems			
Mild other mental problems	0.06	.806	1.06
Moderate other mental problems	0.73	.035	2.07
Severe other mental problems	2.14	.000	8.48
No disability			
Mild to partial disability	0.34	.305	1.41
Moderate disability	1.50	.000	4.47
Severe disability	2.09	.000	8.05

How to predict which clients will have challenging behaviour?

If a clinician has information pertaining to variables contained in Table E.1 for an individual client, then the probability of that client having challenging behaviour can be computed. This is done by adding the B-values in the table to the constant of the binary logistic model, which is -2.65. This will determine the log-odds of challenging behaviour for individual clients (formally represented by the letter z). The value of z can then be used to determine the probability of having challenging behaviour for individual cases using the formula: ez/1+ez, where ez is the exponent of z.

Case example:

A male TBI client does not have any history of drug and alcohol abuse but he does have mental health co-morbidity, specifically severe depression. He also has moderate cognitive problems and moderate disability.

For this client the only relevant B-values relate to moderate cognitive problems, moderate disability and severe depressive symptoms. By adding these values to the constant -2.65 we obtain z=-2.65 + 1.51 + 2.09 + 0.94 = 1.89. Using z we can then calculate that this client has 87% probability of demonstrating challenging behaviour (e1.24/1+e1.24=0.87).

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