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

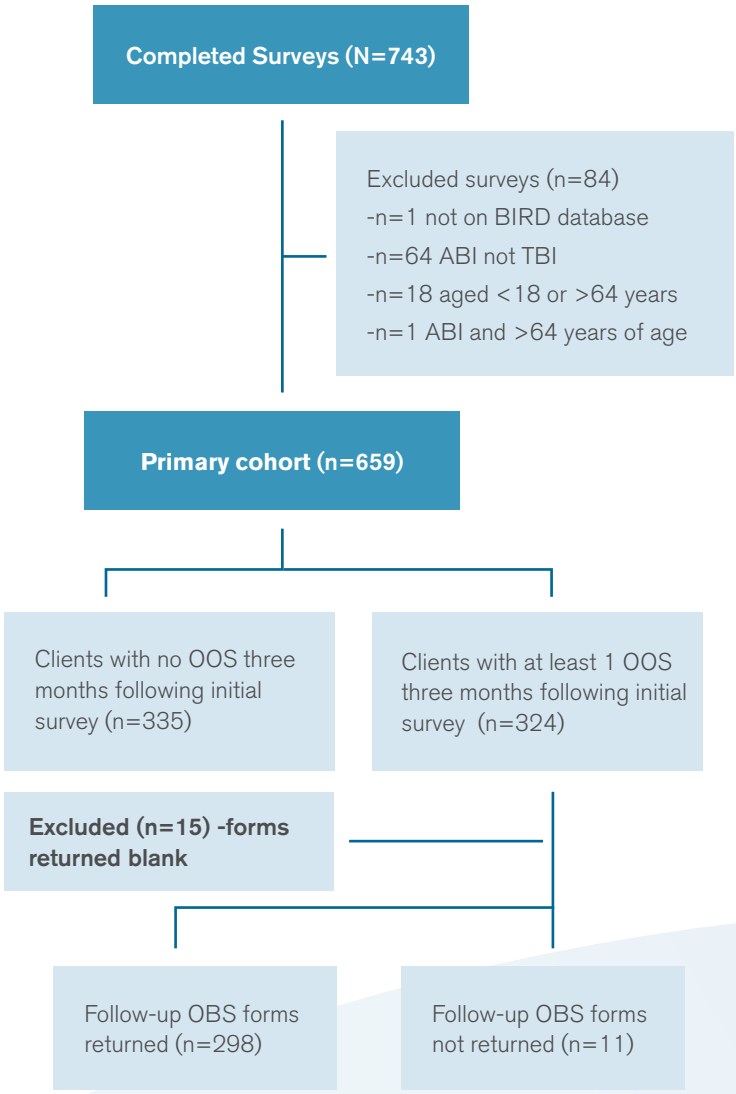
Another stage of the CBP was to have each of the 11 BIRP services identify up to four clients considered particularly challenging in terms of behaviour for qualitative review. It was expected that a thorough review of this select group of clients may provide additional information about challenging behaviours 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.

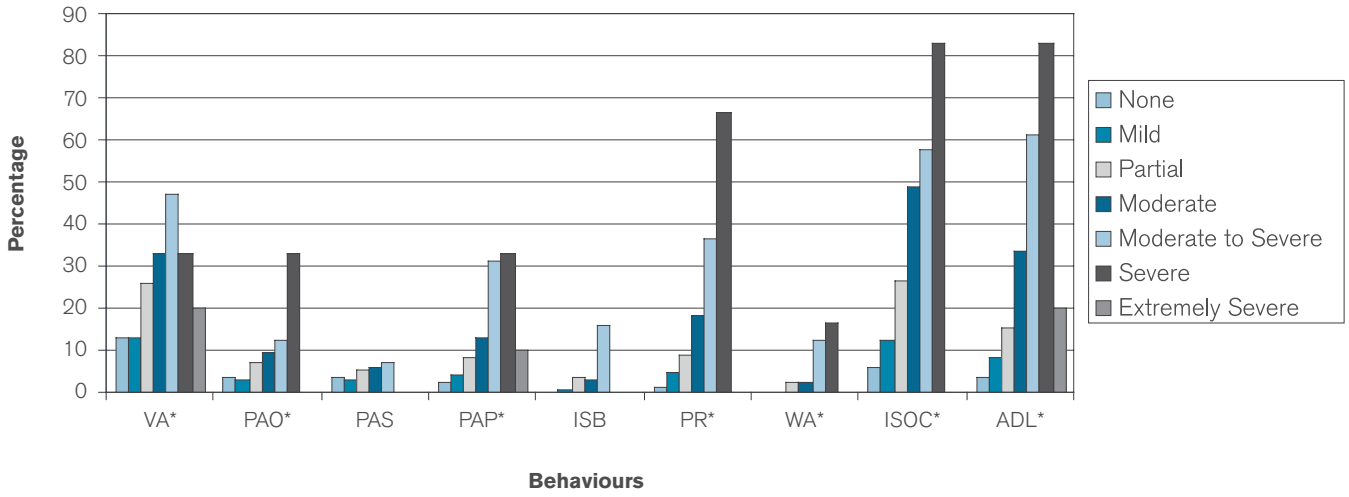
Post-traumatic amnesia

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.

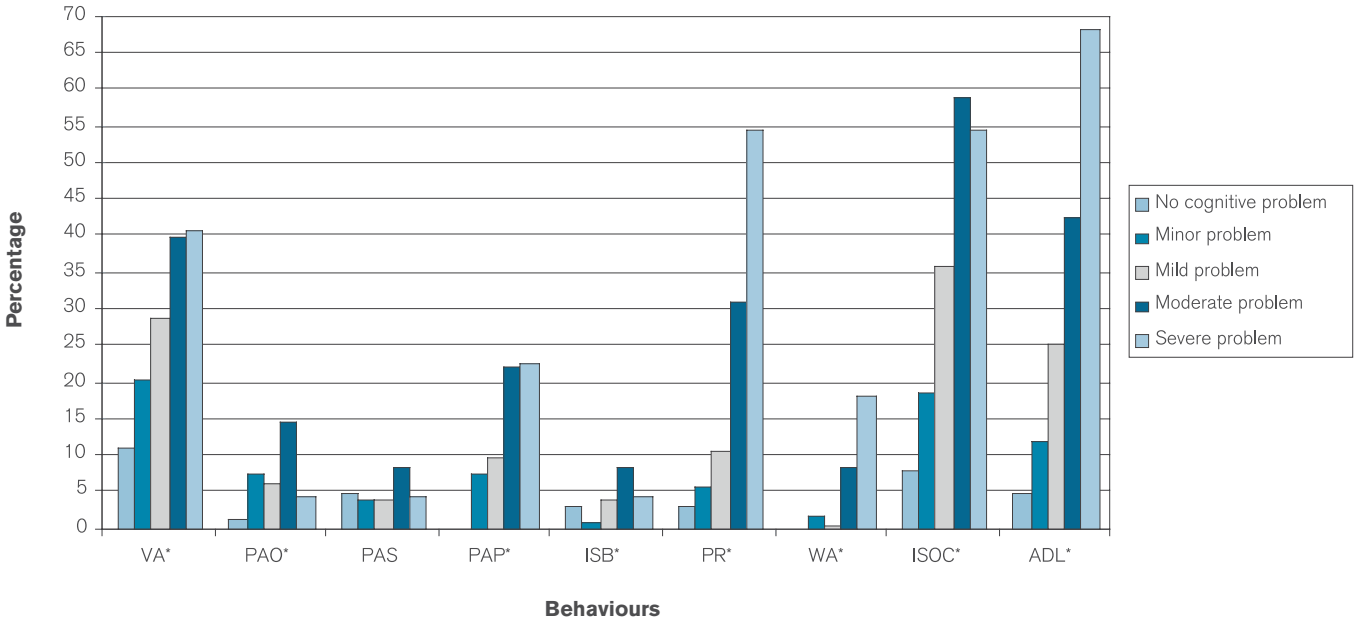
2. There is generally a lower rate of challenging behaviour for those with extremely severe disability.

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.

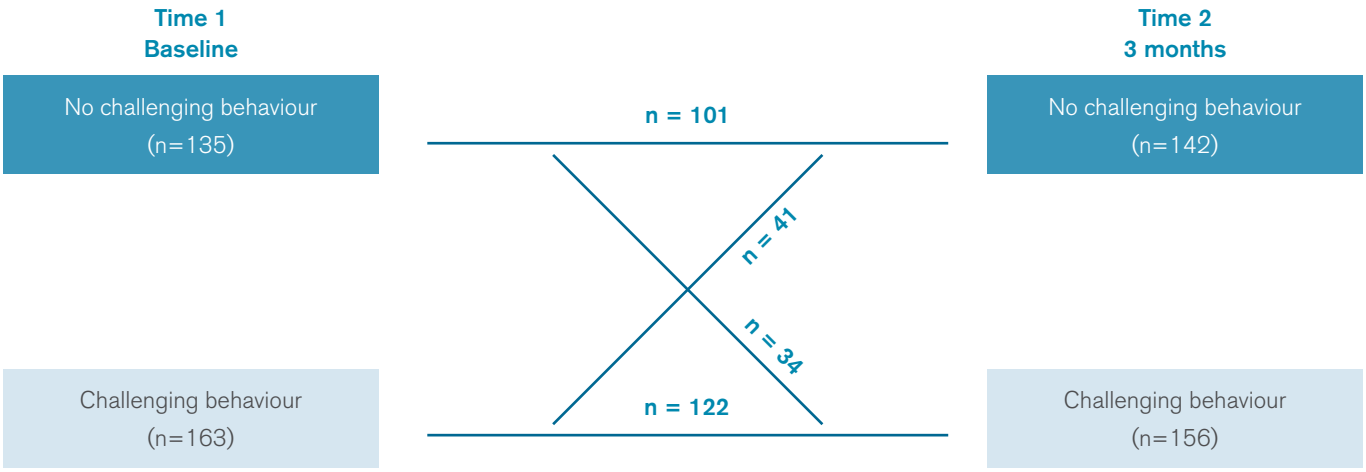
As can be seen in Figure 5, of the 298 clients with valid follow-up OBS data, 223 (74.8%) did not change their behavioural classification:

- 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.

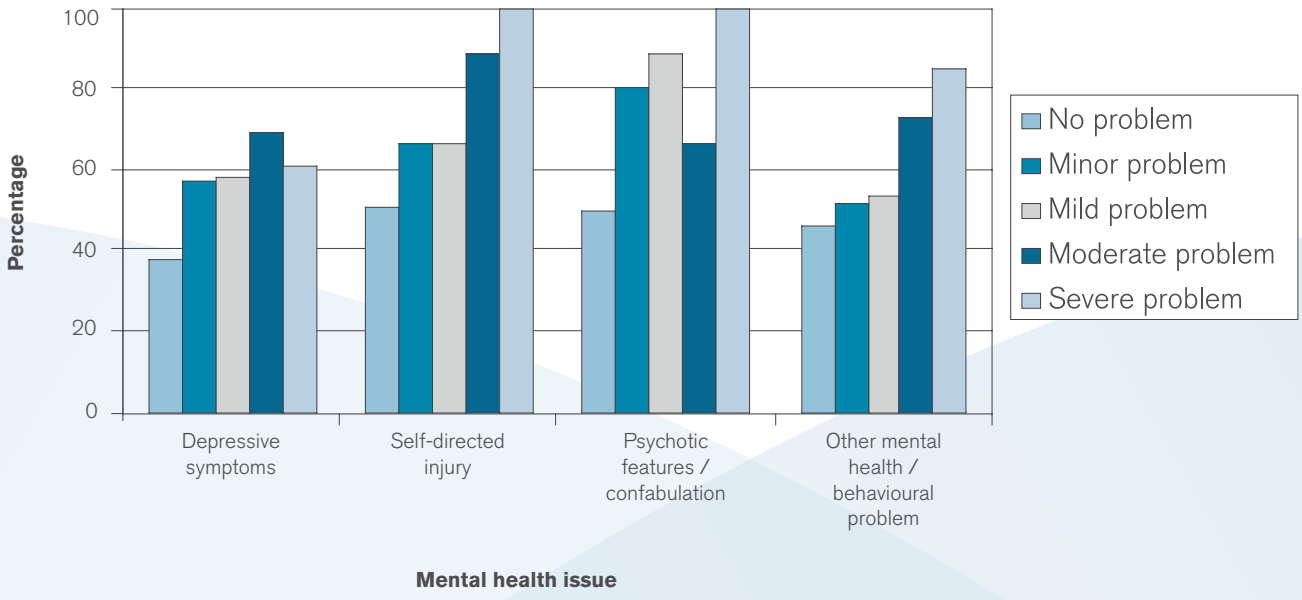
Challenging behaviour was significantly related ($p<0.05$) to:

- 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.

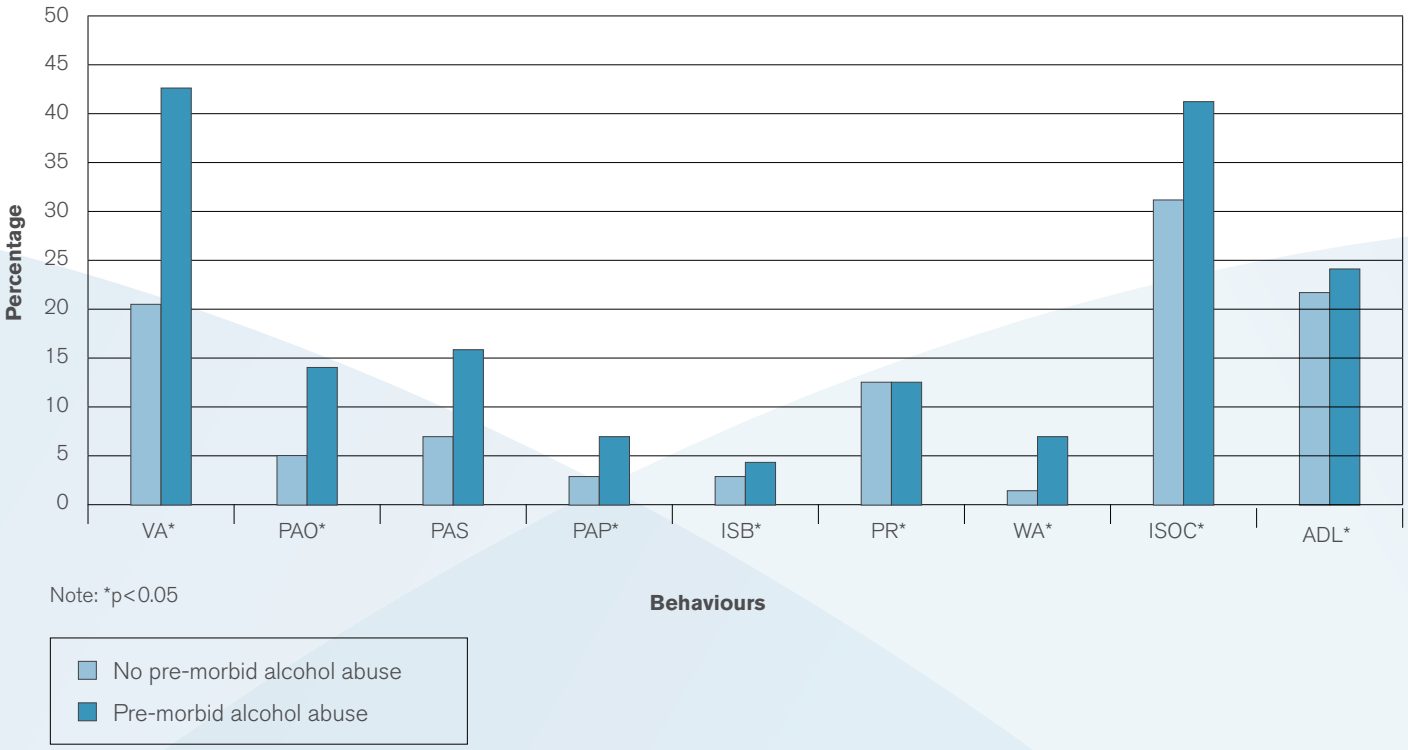
Pre-morbid alcohol and psychiatric history

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).

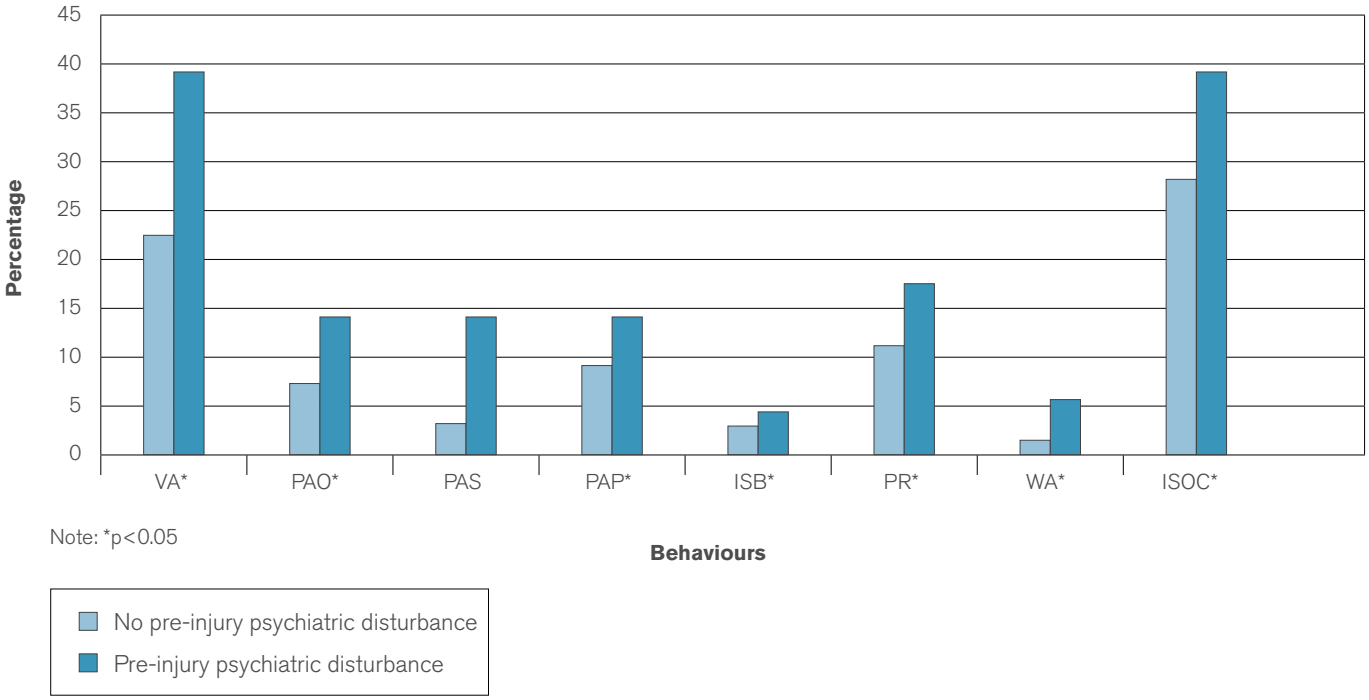
Similarly, a total of 72.0% of clients with a pre-injury history of significant psychiatric disturbance had post-injury challenging behaviour, compared with 50.0% of clients without such a history ($p<0.05$). The rate for different types of challenging behaviour was also associated with clients' pre-morbid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

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



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

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

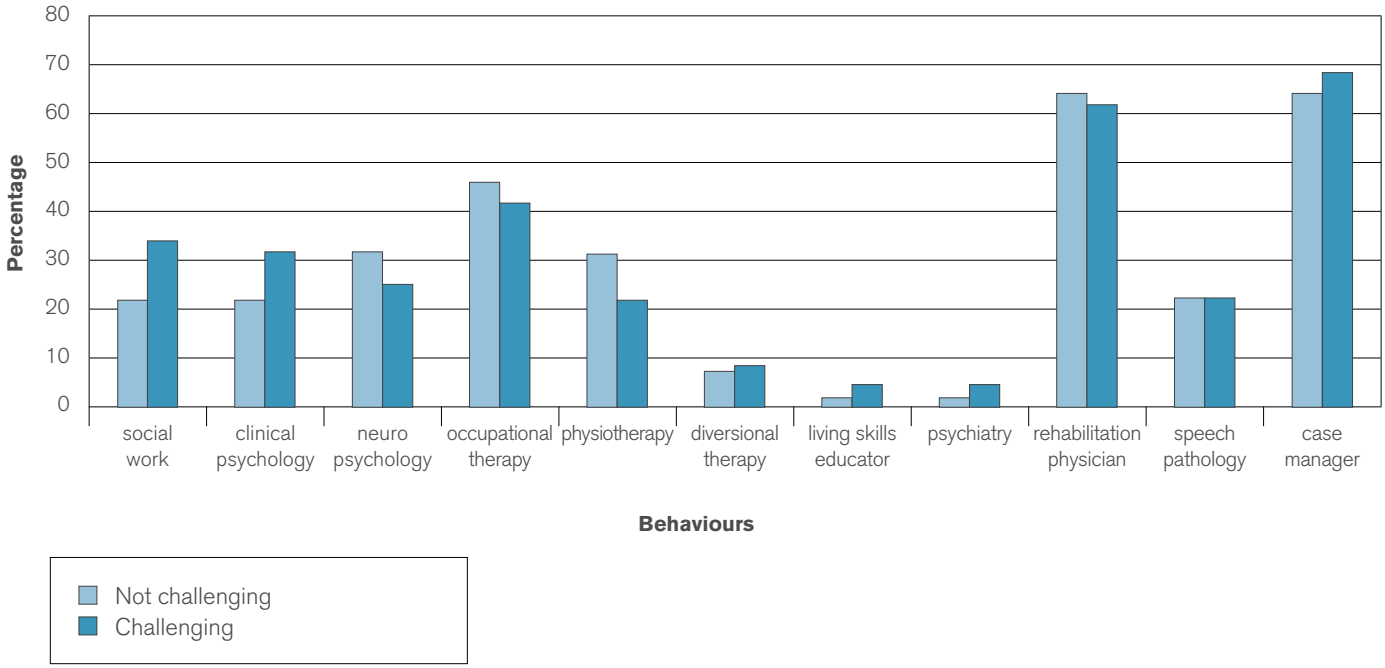
Although clients with co-morbid mental health and drug and alcohol problems were more likely to have challenging behaviour, challenging behaviour is also associated with a variety of other demographic and clinical variables, as shown on pages 12-16. Therefore, co-morbid problems were examined to determine 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.

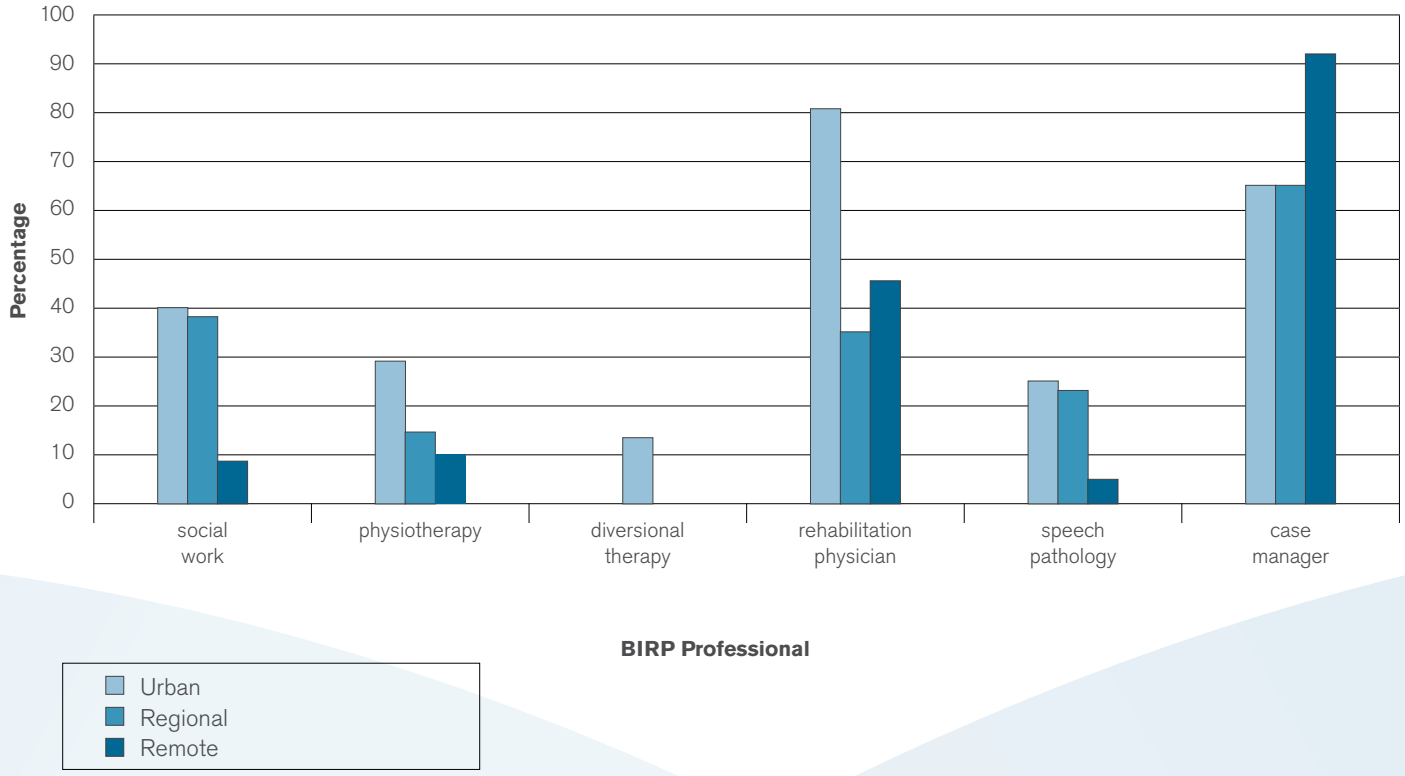
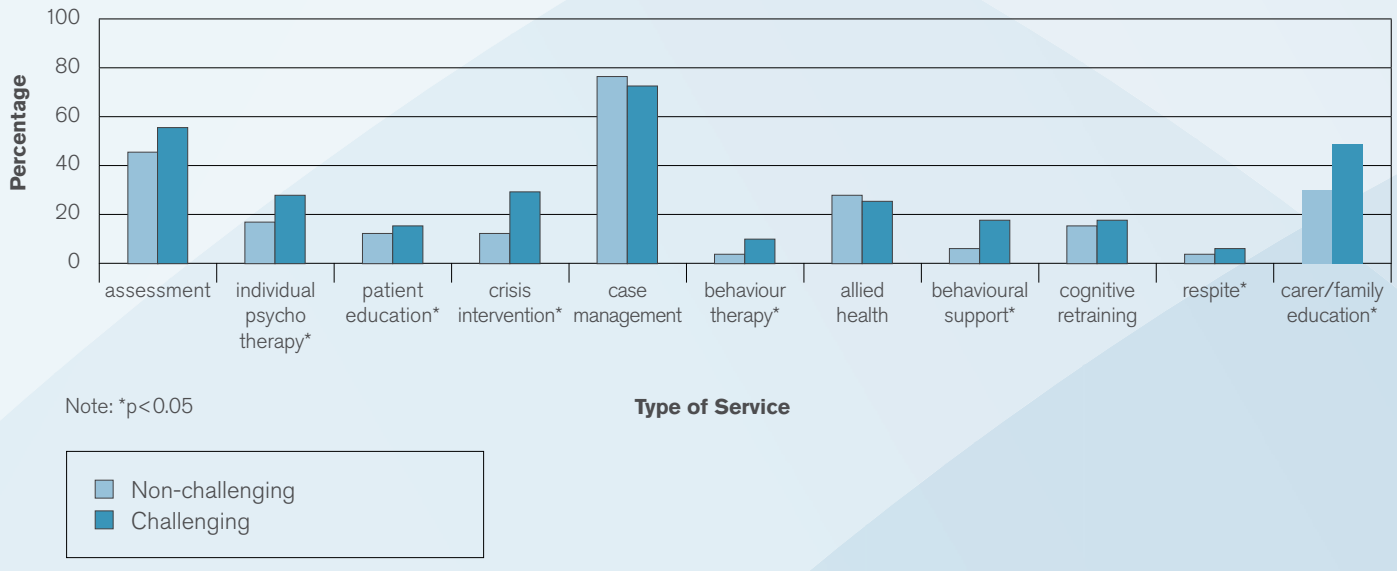
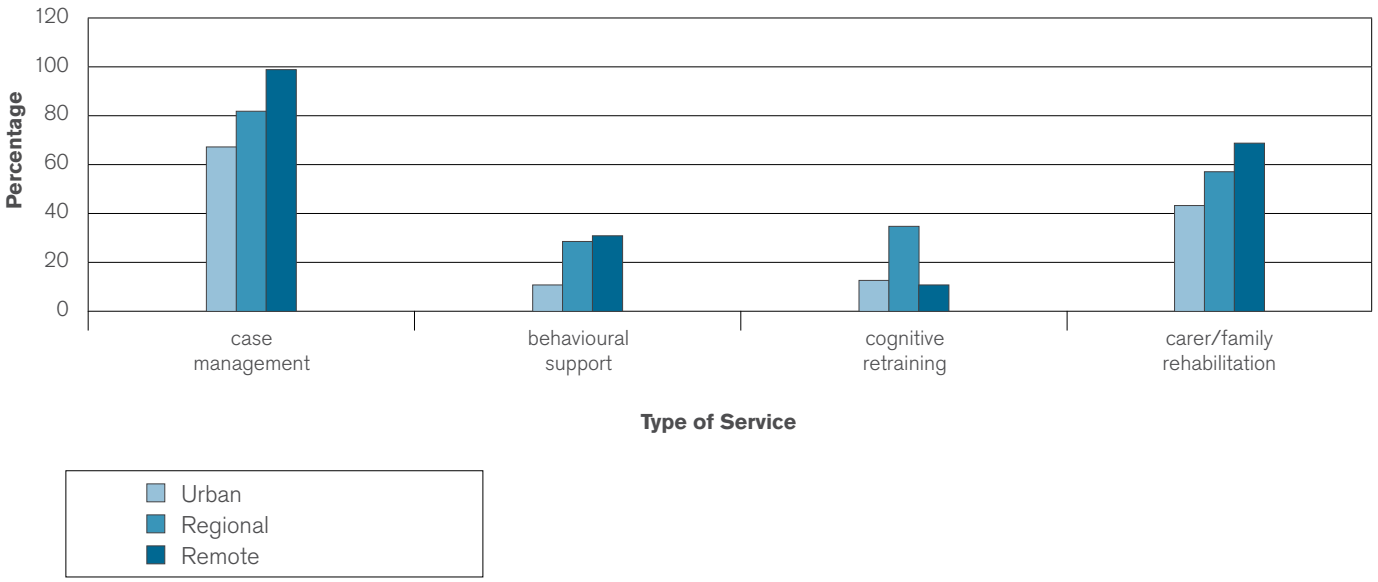


Figure 11: Challenging behaviour by clinical informant services.



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.

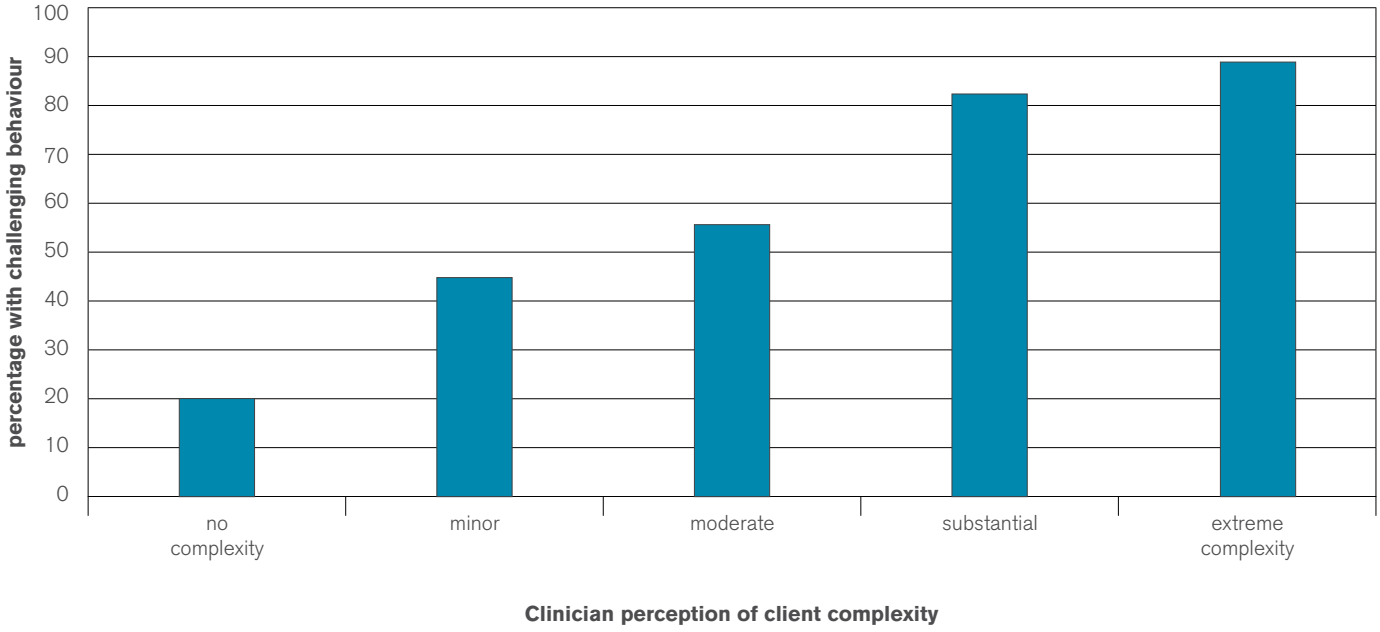


Figure 15: Client complexity by client geographic location.

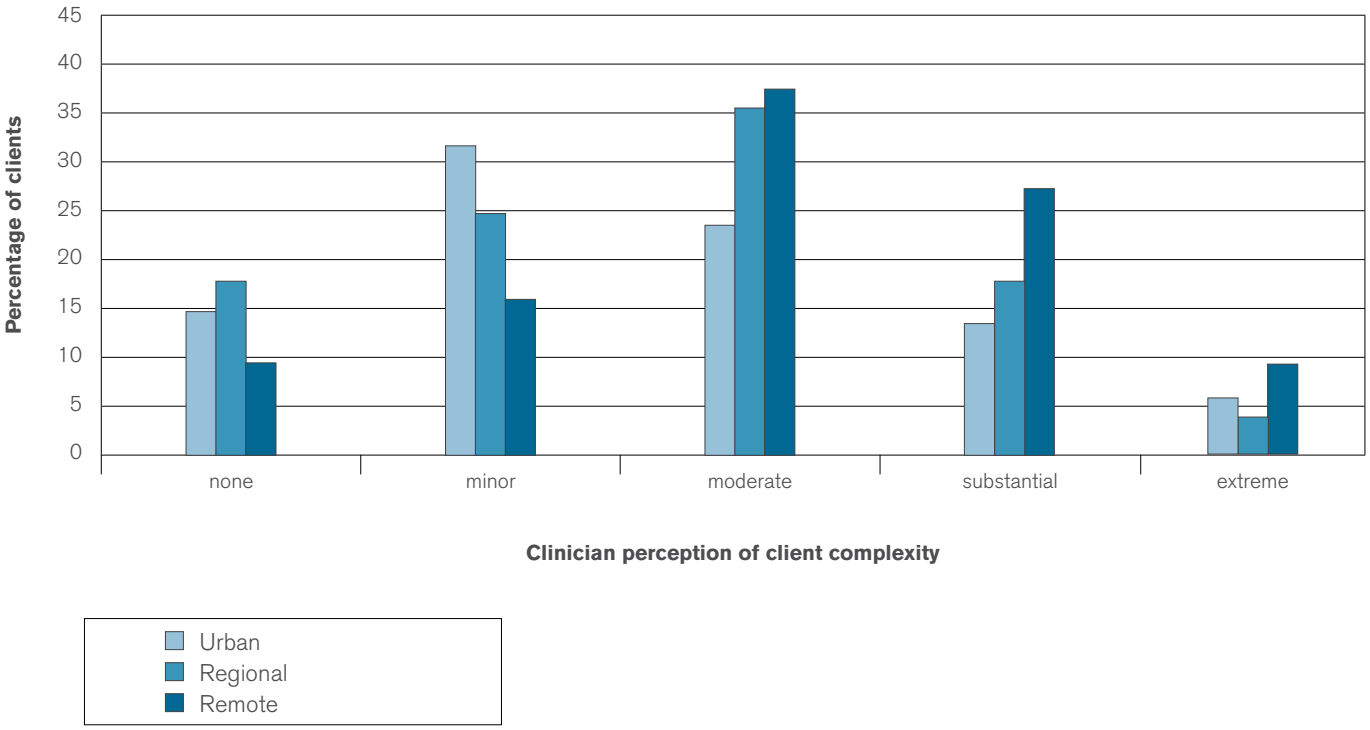
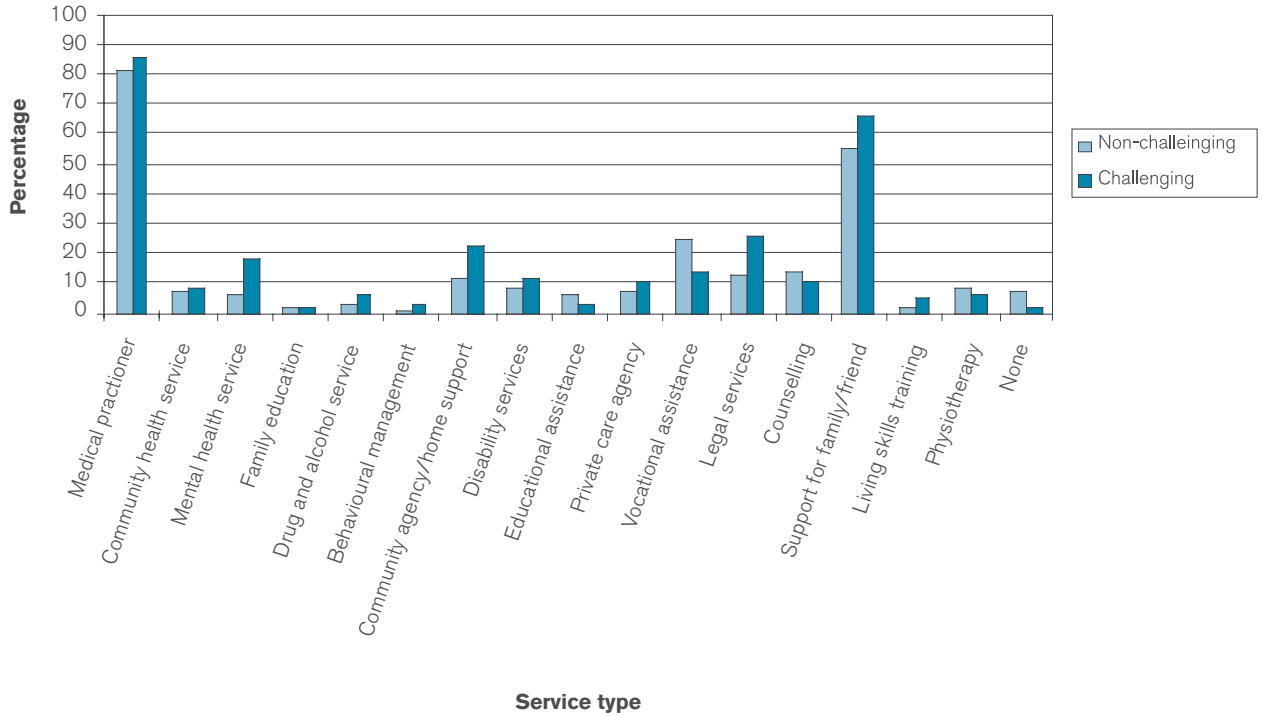


Figure 16: Challenging behaviour by accessed/received non-BIRP services.



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.

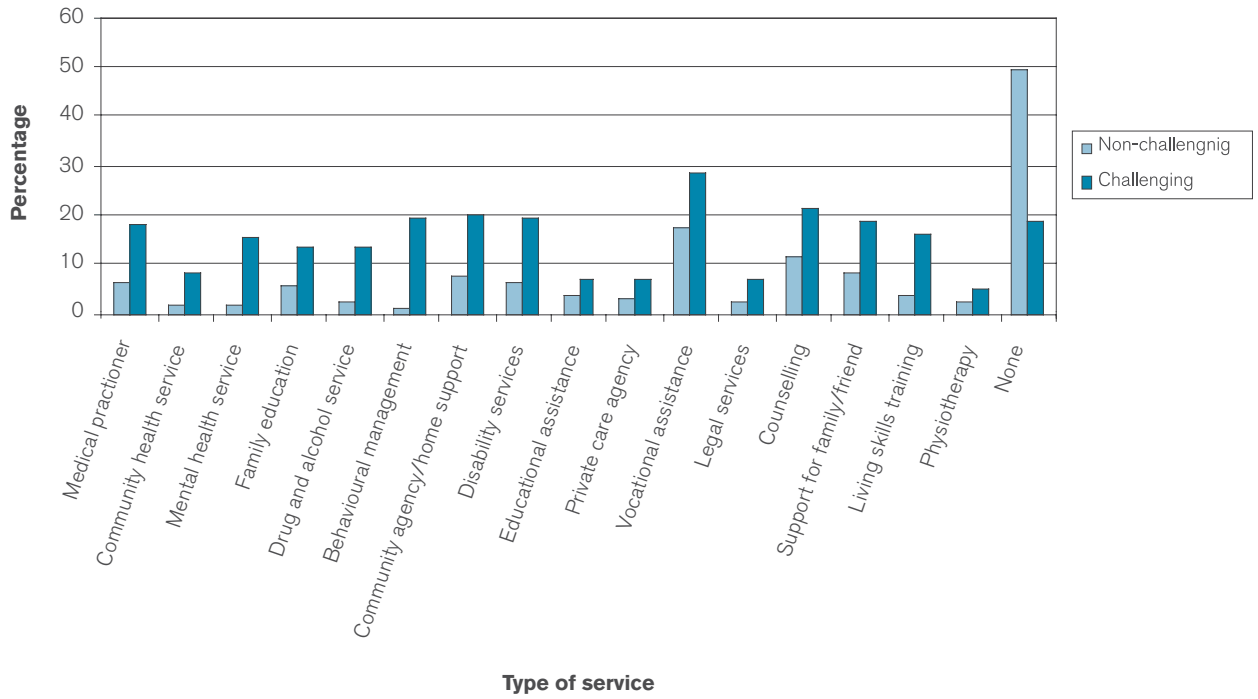
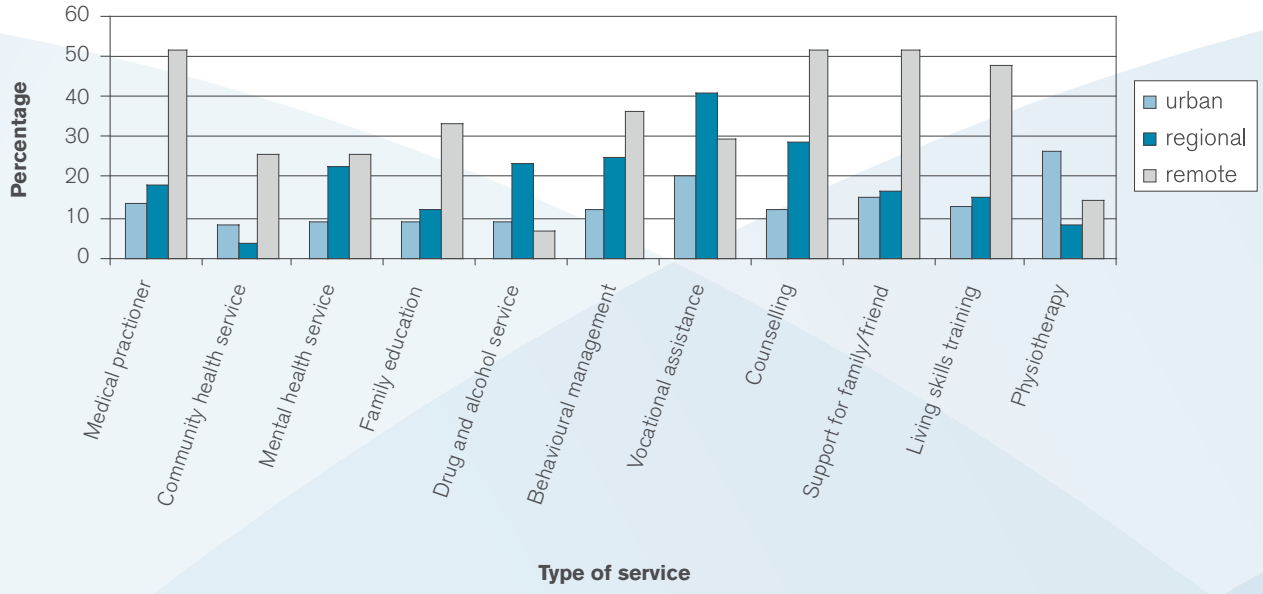


Figure 18: Desired non-BIRP services by location of challenging behaviour clients.



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