



**ACI** NSW Agency  
for Clinical  
Innovation

NSW Brain Injury Rehabilitation Program

# **CHALLENGING BEHAVIOURS PROJECT: PAEDIATRICS**

Using the analysis of  
prevalence and burden to  
inform the model of care

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For further details on the ACI visit:

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# ABBREVIATIONS

<b>ABI</b>	Acquired Brain Injury
<b>ADL</b>	Adynamia/Lack of Initiation ( <i>scale of OBS</i> )
<b>ADHC</b>	NSW Department of Human Services. Aging, Disability and Home Care
<b>AVO</b>	Apprehended Violence Order
<b>BIRD</b>	Brain Injury Rehabilitation Directorate
<b>BIA</b>	Brain Injury Association of NSW
<b>BIRP</b>	Brain Injury Rehabilitation Program
<b>BIRS</b>	Brain Injury Rehabilitation Service
<b>CB</b>	Challenging Behaviour
<b>CBP</b>	Challenging Behaviour Project
<b>D&amp;A</b>	Drug and Alcohol
<b>GCS</b>	Glasgow Coma Scale
<b>GMCT</b>	Greater Metropolitan and Clinical Taskforce
<b>ISB</b>	Inappropriate Sexual Behaviour ( <i>scale of OBS</i> )
<b>ISOC</b>	Inappropriate Social Behaviour ( <i>scale of OBS</i> )
<b>MBA</b>	Motorbike Accident
<b>MH</b>	Mental Health
<b>MVA</b>	Motor Vehicle Accident
<b>NSW</b>	New South Wales
<b>OBS</b>	Overt Behaviour Scale
<b>OBS-K/Kids</b>	Overt Behaviour Scale - Kids
<b>OOS</b>	Occasions of Service
<b>PAO</b>	Physical Aggression against Objects ( <i>scale of OBS</i> )
<b>PAP</b>	Physical Aggression against other People ( <i>scale of OBS</i> )
<b>PAS</b>	Physical Aggression against Self ( <i>scale of OBS</i> )
<b>PR</b>	Perseverative/Repetitive Behaviour ( <i>scale of OBS</i> )
<b>PTA</b>	Post Traumatic Amnesia
<b>TBI</b>	Traumatic Brain Injury
<b>VA</b>	Verbal Aggression ( <i>scale of OBS</i> )
<b>WA</b>	Wandering/Absconding Behaviour ( <i>scale of OBS</i> )



# FOREWORD

The ACI's Challenging Behaviour Project addresses an important aspect of one of the more difficult and costly issues for the health system and the community — the management of children and young adults with Traumatic Brain Injury (TBI).

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

The project addressed the needs of adults and children separately.

The Paediatric Project involved collection of information on 182 clients aged between eight and 18 years with a primary diagnosis of TBI between February 2007 and December 2009, plus a qualitative case review of 10 clients from the three paediatric BIRP services.

The results suggest the need for improvements in the model of care for better early detection of challenging behaviour to enable intervention before problems become entrenched. Additionally, unique issues were identified to tackle developmental, parenting and educational issues that can contribute to challenging behaviours.

The project developed eight key principles for integration into current models of service delivery, and 43 recommendations for an improved model of care for paediatric clients with, or at risk of developing, 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 water accidents.

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

TBI can derail the normal developmental trajectory for children and adolescents, resulting in difficulties with learning and education; forming and maintaining friendships and relationships; and achieving long-term life goals.

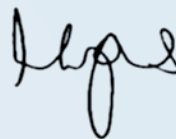
The total cost to the Australian community through direct care and lost productivity has been estimated by Access Economics (2009) at more than \$8.6 billion a year. Almost two thirds of the cost is shouldered by individuals and families either directly or through insurances.

The ACI project found that there is a complex interaction between medical, psychological, social, environmental and in the case of children and adolescents unique developmental 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 were collected separately for adults and children and are 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 paediatric report describes a two-stage study undertaken by the Brain Injury Rehabilitation Directorate, Agency for Clinical Innovation (ACI) to collect data on prevalence and burden of challenging behaviours in paediatric 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 modes of service delivery and 43 recommendations for changes or enhancement to the existing model of service delivery for paediatric clients with, or at risk of, 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 units and three paediatric units offering inpatient and community services. Adult units also have a transitional living service.

The BIRD was established as an ACI clinical network in 2002 to collaborate with the adult and paediatric metropolitan BIRP services to identify how and where improvements are needed for delivering safer and better care.

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 paediatric admissions and was able to involve clinicians from each paediatric service in the study to collect additional information relating to challenging behaviours.

## METHODOLOGY

The Challenging Behaviours Project (CBP) 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 concerning 182 paediatric clients who met criteria for inclusion in the study. Children included in the study had: a primary TBI diagnosis; were aged between 8 and 18 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, and level of servicing.

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

## RESULTS

### Prevalence

The project found the prevalence of challenging behaviour after TBI to be high; 51% of clients in the study met criteria for challenging behaviour. The most prevalent challenging behaviour was inappropriate social behaviour (37%), followed by verbal aggression (30%); adynamia/lack of initiation (15%); wandering/absconding (14%); physical aggression against others (14%); physical aggression against objects (13%); inappropriate sexual behaviour (12%); perseverative/repetitive behaviour (6%); and physical aggression against self (4%).

### Burden

The burden of challenging behaviour was demonstrated in the study in terms of increased demand on services, elevated level of unmet service need, and perceptions by clinicians of high stress and complexity working with children with challenging behaviour.

Clinical psychology and neurology were the two BIRP professions that provided significantly higher level of service to children with challenging behaviour than to children without challenging behaviour. In terms of specific BIRP services available, children

with challenging behaviour received significantly more psycho-education, crisis intervention, behaviour therapy and behavioural support services than children without challenging behaviour. This increased level of servicing by the BIRP no doubt contributed to clinician perceptions of increased stress and complexity working with challenging behaviour clients. Of clients with whom working was not perceived as stressful or complex, only 15% had challenging behaviour. In contrast, all the clients perceived by clinicians to cause severe levels of stress and be extremely complex to work with had challenging behaviour.

Children with challenging behaviour also placed more demand on services external to the BIRP. Children with challenging behaviour were also more likely to have unmet service needs in accessing or utilising non-BIRP services compared to children without challenging behaviour. Moreover, the project showed that children with challenging behaviour living in remote and regional parts of the state were more disadvantaged in the level of services they received and level of unmet need compared with their urban counterparts.

#### Themes associated with challenging behaviour

The qualitative review of 10 BIRP paediatric 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, while another cluster described the consequences of challenging behaviour — See following diagram and figure 10.

The results of the CBP led to the development of eight principles considered important in the implementation of a Model of Care for children with challenging behaviour after TBI. These principles are presented below, along with recommendations for service enhancements and changes that would allow implementation by the BIRD, BIRP and non-BIRP agencies.

## CONSEQUENCES OF CHALLENGING BEHAVIOUR

Themes included consequences such as lack of engagement in the educational system, exclusion from participation opportunities, decline in family adjustment and cohesion, and problems achieving developmental milestones.

## DEVELOPMENT & MAINTENANCE OF CHALLENGING BEHAVIOURS

### Family adjustment issues

Themes included that family psychosocial problems, adaptability, level of skill in consistent/positive parenting, socio-cultural background and level of engagement in services contribute to challenging behaviours.

### Child characteristics

Themes included that premorbid behavioural/learning difficulties, lack of client insight and motivation, level of fatigue, level of impairment and disability and stage of development contribute to maintaining challenging behaviour.

### Environmental factors (non-family)

Themes included that environmental stressors, level of educational support and appropriateness of educational placement, level of participation, quality of peers and geographical proximity to services affect expression of challenging behaviour.

### Medical issues

Themes included medical complications and drug, alcohol and mental health issues contributing to challenging behaviour presentation.

## **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 paediatric 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:**

BIRP needs to increase the provision of behaviour management programs (e.g. formal social skills retraining and anger management programs) to respond to the high prevalence of socially inappropriate and aggressive challenging behaviours after childhood TBI.

### **Recommendation 3:**

BIRP services need additional resources to be able to adequately evaluate the effectiveness/outcomes of behavioural management plans so they can promptly respond 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.

### **Recommendation 5:**

BIRP services need to strengthen and maintain their relationship with community referral and support networks to improve access for children and families dealing with challenging behaviour.

## **PRINCIPLE 2:**

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

### **Recommendation 6:**

BIRP needs to ensure a consistent and multi-disciplinary approach to the management of clients where the psychosocial environment and/or cognitive, language and physical functioning of clients are recognised as the context of challenging behaviours.

### **Recommendation 7:**

BIRP services need to ensure the availability of skilled staff as part of a multi-disciplinary team to provide behavioural management services that consider the developmental, family, educational and community context in which these behaviours occur.

## **PRINCIPLE 3:**

Clients require adequate levels of long-term care, support and environmental modification

### **Recommendation 8:**

A network of BIRP paediatric co-ordinators is needed to facilitate access to needed care and support services within the local community.

### **Recommendation 9:**

There is a need to advocate for increased in-home services so that families can sustain their role in providing care and support to children and adolescents with TBI.

### **Recommendation 10:**

BIRP needs to be better equipped to provide families with home-based interventions so the families are enabled to provide the necessary supports for children.

### **Recommendation 11:**

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

### **Recommendation 12:**

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

**Recommendation 13:**

BIRP needs to undertake comprehensive assessment of families' adaptive skills and capacity to provide positive parenting to their child post-TBI.

**Recommendation 14:**

BIRD should develop standard challenging behaviour education program(s), e.g. workshop(s), for family and ancillary services that care for paediatric clients with TBI.

**Recommendation 15:**

There is a need to increase the range of respite services available to strengthen the capacity of families to manage children with challenging behaviour by improving access to existing respite services and developing new approaches to respite.

**Recommendation 16:**

BIRD needs to liaise with the BIA to explore options about advocacy for improved access to appropriate services (e.g. emergency respite; educational support; family support) to meet the needs of children with TBI and maintain a positive family environment.

**Recommendation 17:**

BIRD needs to promote state-wide education programs for teachers and educational authorities, government and non-government alike, to increase their awareness of issues relevant to children with TBI and how best to support them so their learning is not disadvantaged.

**Recommendation 18:**

BIRD needs to advocate for access to a functional assessment-based approach to funding educational support needs that considers the behavioural, emotional and executive impairments (not only IQ) that impact on learning and day-to-day functioning of children with TBI, so as to help ensure the delivery of adequate levels of educational support and teacher's aide hours.

**Recommendation 19:**

BIRD needs to advocate for an expansion of learning support teams so children with TBI can have access to special classroom resources to maximise their learning and reduce occurrence of challenging behaviour.

**PRINCIPLE 4:**

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

**Recommendation 20:**

BIRD needs to support the implementation of protocols for assessment of premorbid and current issues which will aid in the assessment of risk of clients developing challenging behaviour. This should include systematic assessment of premorbid behaviour, mental health and medical comorbidity, family functioning, cultural identity, developmental levels and level of impairment and disability.

**Recommendation 21:**

BIRP services need to identify the indigenous status of clients so they can involve and collaborate with the Aboriginal Health Service and other indigenous service providers when working with indigenous TBI clients.

**Recommendation 22:**

BIRP services need to routinely assess the mental health status of paediatric clients including depression, anxiety and emotional adjustment, and make referrals to appropriate mental health services as soon as possible.

**Recommendation 23:**

BIRP services need to liaise with multicultural health services when engaging with clients from culturally and linguistically diverse backgrounds.

**Recommendation 24:**

BIRP staff need to advocate for access and support for children in non-BIRP health and other required services (e.g. respite, behavioural support services, family and parenting support, community trained staff).

**Recommendation 25:**

BIRD needs to develop education programs that will support other services that come into contact with paediatric TBI clients to increase their awareness of TBI issues and how to be able to successfully provide services to paediatric TBI clients.

## **PRINCIPLE 5:**

There is a need for equitable access to all services throughout NSW based on need

### **Recommendation 26:**

BIRP services that cater for more geographically isolated clients need to have the option of providing behavioural services for children, and/or for there to be an increase in resources to enable staff from these services to travel to remote areas.

### **Recommendation 27:**

All BIRP services need an appropriate number and skill mix of case managers and/or social workers to manage family and ancillary carer issues.

### **Recommendation 28:**

There is a need to increase psychological services within paediatric BIRP services to deal with the presentation of emotional and behavioural issues after TBI.

### **Recommendation 29:**

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

### **Recommendation 30:**

BIRP needs to increase its capacity to provide a network of rehabilitation coordinators to support staff in other services in more geographically isolated areas where there is currently minimal or no infrastructure support for children with TBI and their families.

### **Recommendation 31:**

BIRD needs to liaise with ADHC and other relevant service providers to explore options about improving access to services for children with TBI in remote/regional parts of the state.

### **Recommendation 32:**

BIRD to explore with BIRP services barriers to why children with challenging behaviour in regional/remote areas are not receiving the support required to access vocational assistance.

## **PRINCIPLE 6:**

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

### **Recommendation 33:**

Special school counsellor (brain injury) roles need to be expanded (multiple and full-time) so there is a consistently available interface between rehabilitation and education to improve learning outcomes.

### **Recommendation 34:**

There is a need to develop well defined and consistent communication pathways between BIRP services and schools (through learning support teams or equivalent structures in independent and Catholic schools) regarding individual children with TBI.

## **PRINCIPLE 7:**

Specialised assessment and management is required for challenging behaviours in the TBI paediatric population.

### **Recommendation 35:**

BIRP needs to maintain capacity and have adequate availability of skilled staff in metropolitan and rural NSW. Skilled staff will consider a range of behavioural management approaches for intervention and integrate them in the family and developmental context in which the behaviours occur.

## **PRINCIPLE 8:**

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

### **Recommendation 36:**

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

**Recommendation 37:**

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

**Recommendation 38:**

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

**Recommendation 39:**

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

**Recommendation 40:**

The capacity of disability and generic leisure and recreation service providers to accommodate children with TBI and challenging behaviour should be increased.

**Recommendation 41:**

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

**Recommendation 42:**

BIRP staff need to be able to access the range of social technologies available for undertaking therapies that will promote clients developing and sustaining social networks.

**Recommendation 43**

To improve the current paediatric model of care in the NSW BIRP, a Behaviour Support and Development Service is required that would initially focus its efforts in more remote parts of NSW where there is currently little or no behavioural management support.

**Implementation of the recommendations**

The scope of the above recommendations requires a planned and integrated approach to implementation. It is suggested that the most practical and efficient way to effectively implement the principles into the current BIRP model of care would be to establish a Behaviour Support and Development Service (BSDS) that includes children. 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. Moreover, the BSDS will need to be able to flexibly provide services to a wide age range of clients including children and adolescents where the variability of behavioural presentations will be determined by developmental, attachment, family and educational issues. These services will need additional resources to ensure equity across health districts and in rural and remote locations.

The proposed BSDS will also require additional resources to enable an expansion of the scope of the current paediatric 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 change in different environments. This support will include:

- Assessment of needs of challenging-behaviour clients and their families
- Development of behaviour management plans
- Intensive program implementation in home and community environments (e.g. at school)
- Support to and supervision of 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, teachers, ancillary carers and BIRP staff
- Education and training of other non-BIRP service providers.

It will be essential for the BSDS 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 clients 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, allied health staff, teachers.

The recommended BSDS would provide an organisational structure for ensuring the principals and recommendations for service delivery, workforce and policy are adopted and implemented.

# 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 children challenging behaviours are associated with learning difficulties, poor educational engagement, increased costs in managing such clients and significant distress for family and staff exposed to such behaviours, as well as the child and adolescent with TBI (Anderson, Catroppa, Haritou, Morse, Pentland, Rosenfeld & Stargatt, 2001; Hawley, 2004; Taylor, Yeates, Wade, Drotar, Stancin & Burant, 2001). There is evidence that the course of these behaviours can persist for many years post-injury and even worsen over time; this has been consistently shown for those children with more severe injuries (Kinsella, Ong, Murtagh, Prior & Sawyer, 1999; Schwartz, Taylor, Drotar, Yeates, Wade & Stancin, 2003). Unfortunately, the prevalence of such behaviours in children and adolescents is poorly understood as studies to date have used measures of challenging behaviour that have been developed for the psychiatric population rather than for children with acquired or traumatic brain injury (e.g., Anderson et al., 2001; Kinsella et al., 1999; Schwartz et al., 2003). The Challenging Behaviour Project (CBP) was devised to address these gaps in the literature and achieve the following aims<sup>1</sup>:

1. Develop a measure for the assessment of challenging behaviour in paediatric TBI clients
2. Establish the prevalence of challenging behaviour among paediatric TBI clients
3. Examine the burden of challenging behaviours on the client, family and services managing clients

The CBP was important for the following reasons:

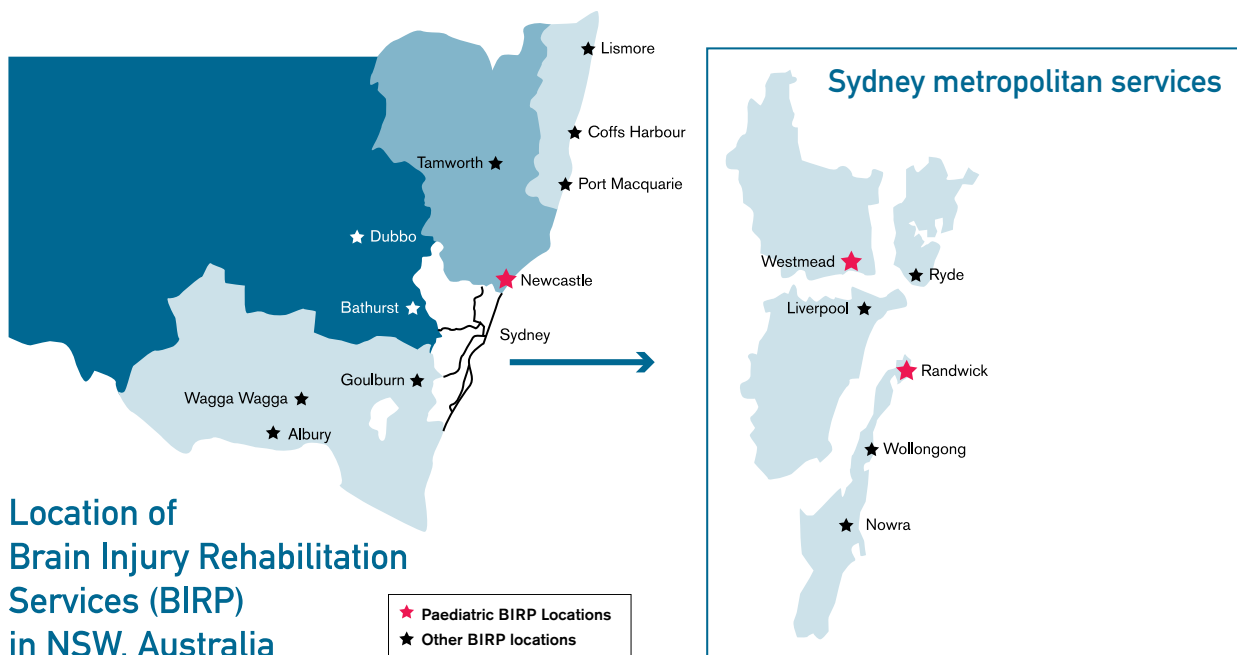
- Challenging behaviour was identified by the Brain Injury Rehabilitation Program (BIRP) as one of the top state-wide priorities requiring urgent attention
- To create an evidence base for coordinated state-wide management of challenging behaviours among people with TBI that will have flow-on effects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

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<sup>1</sup> A fourth aim of the project was to determine the course of challenging behaviour over a three-month follow-up interval, as was done in the adult project. However, very limited data were available for analysis as the clinical pathways within paediatric services meant that a significant proportion of clients were not followed up within a three-month time frame. Therefore, data pertaining to course are not presented because of insufficient numbers.



**Figure 1: Locations of Paediatric Metropolitan BIRP Services**



**Context of the current study**

Approval and financial support to undertake the Challenging Behaviour 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 22 specialist clinical networks in NSW that together aim to improve healthcare via clinician and consumer involvement in continuous clinical redesign.

The Brain Injury Rehabilitation Directorate (BIRD) was established as an ACI clinical network in 2002 and collaborates with the existing adult and paediatric services that make up the NSW BIRP to identify how and where improvements are needed for delivering safer and better care. The location of individual BIRP services can be viewed in Figure 1.

The NSW BIRP provides inpatient, transitional<sup>2</sup>, community and paediatric services. Each BIRP service submits electronic demographic and clinical data for client admissions to the BIRD for reporting. The CBP was able to access this information for all paediatric admissions to the NSW BIRP and involve clinicians from each service in the study.

The current report presents the findings of the paediatric arm of the Challenging Behaviours Project, or CBP. Findings of the adult arm of the project are published separately.

<sup>2</sup>Transitional living units are only available at selected adult BIRP services.

# METHODS

**Sample**

The sample for the study was recruited from BIRP's three metropolitan paediatric services. The following criteria used to identify paediatric BIRP clients for inclusion in the study:

- Clients had to be aged between 8 and 18 years of age
- Clients had to be community clients, not inpatients
- Clients had to have had at least three occasions of service (OOS) over the 12 months prior to recruitment into the study
- Clients had to 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 related site-specific approval to undertake this study was provided by each of the services involved.

**Measures**

The Overt Behaviour Scale (OBS) was designed to document in standardised fashion different types of observable challenging behaviours in adults following TBI (Kelly, Todd, Simpson, Kremer & Martin, 2006). This instrument was adapted specifically for the paediatric arm of the CBP so that it could assess the behavioural changes following childhood TBI. This new instrument was called the Overt Behaviour Scale – Kids (OBS-K). The changes made to cater for the paediatric population generally related to providing

clearer examples of overt behaviours at different severity levels that may apply to children (e.g. leaving school grounds; refusing to go to school; prompting by a teacher; repeatedly asking if they can go to McDonalds). No items were removed from the OBS to cater for children but one item was added (faecal smearing) under the “inappropriate social behaviour” section of the OBS-K.

The OBS-K assessed the same nine categories of challenging behaviour covered by the OBS including 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. Like the OBS, the OBS-K required respondents to rate the severity, frequency and perceived impact of each of the nine types of behaviours.

Preliminary data were collected to establish the reliability and validity of the OBS-K. This information is provided in Appendix A.

In addition to the OBS-K, a client details form was developed specifically for the paediatric arm of the CBP to obtain specific information about the services accessed or not accessed. Both the OBS-K and Client Details form can be found in Appendix B.

Finally, BIRD's computerised clinical dataset was accessed to obtain demographic and clinical information for each client including gender, age, country of birth, main language spoken, indigenous status, age at injury, injury circumstance and duration of post traumatic amnesia (PTA)<sup>3</sup>.

## Procedure

Forms were completed by 36 BIRP clinicians identified to be the clinical informants for the paediatric clients included in the study. These clinicians were identified because they had the most complete knowledge of each of the clients.

## Identification of challenging behaviour in children and adolescents

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-K, 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-K for this purpose because the nature of these indices was 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-K.

Instead, criteria for challenging behaviour were established with reference to the objective (severity level) and subjective (perceived impact) information available for each of the nine behavioural domains assessed by the OBS-K. It was decided that any developed criteria should reflect the following two 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. Regardless of the objective indicators of behaviour, if behaviour was 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 the adult arm of the CBP a third principle related to the consideration of milder, irritating and disruptive behaviours that posed a minimal risk of injury or threat to the client or others as challenging if they occurred at high frequency (in the adult project the frequency cut-off was when these behaviours occurred at least daily). However, this was not considered a reasonable principle to follow in the paediatric study as daily occurrence or even occurrence multiple times a day of such milder behaviours would not necessarily be developmentally inappropriate for children. Therefore, only the above two listed principles were operationalised into challenging behaviour criteria using the OBS-K:

### *Criterion 1:*

Any OBS-K behaviours rated at severity level 3 or 4 would be considered challenging regardless of frequency. However, for physical acts against self, physical aggression against other people, perseverative and wandering behaviours, severity level 2 will also be deemed challenging regardless of frequency. Any severity level of sexually inappropriate behaviour will be considered challenging. In addition, adynamic/lack of initiation behaviour will only be considered challenging if requiring at least multiple prompts per day (level 4) or all tasks everyday (level 5), because of the tendency for children to often require prompting.

### *Criterion 2:*

If the perceived impact of any OBS-K behaviours is rated as severe or extreme, they would be considered challenging.

Table 1 illustrates the type of behaviours that would be defined as challenging on the basis of the above criteria.

<sup>3</sup> PTA is only assessed in children aged 7 years and over.

**Table 1: OBS-K cut-off criteria for challenging behaviour in children**

	<b>Challenging behaviour at any frequency or when impact perceived severe or extreme</b>	<b>Challenging behaviour only when impact perceived severe or extreme</b>
<b>Verbal aggression</b>	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
<b>Physical aggression against Objects</b>	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
<b>Physical acts against Self</b>	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)	
<b>Physical aggression against Others</b>	4 Causes severe physical injury (fracture, cut)	2 Strikes, kicks, pushes, pulls hair
	3 Causes mild-moderate injury (bruise)	1 Threatening gesture, swings at people, grabs clothes
<b>Inappropriate sexual behaviour</b>	4 Attempt to forcibly undress another person, threat to obtain sex, rape	
	3 Attempt or act of touching other people's genitals	
	2 Masturbation in public	
	2 Exhibitionism in public	
	1 Touching other people who don't want to be touched, kissing hand, patting knee	
	1 Comments of a sexual nature	
<b>Perseveration/ Repetitive behaviour</b>	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 resulting in minor physical harm	

**Table 1 (Continued):** OBS-K cut-off criteria for challenging behaviour in children

	Challenging behaviour at any frequency or when impact perceived severe or extreme	Challenging behaviour only when impact perceived severe or extreme
<b>Wandering/ Absconding</b>	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 resulting in minor physical harm	
<b>Inappropriate social behaviour</b>	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 without a license, stealing cigarettes	1 Socially awkward, inappropriate laughter, failure to monitor personal hygiene, standing too close
	3 Noncompliant or oppositional	
<b>Adynamia/ Lack of initiation <sup>4</sup></b>	4 Multiple prompts per day	
	5 All tasks everyday	

<sup>4</sup> Adynamia/lack of initiation is not rated in terms of severity on the OBS. It is only rated in terms of frequency of prompting.

### 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. Fisher exact tests were used for independent and dependent variable that had two categories or levels.
- Mann-Whitney U test – to analyse the difference between two groups against a dependent continuous variable.

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

### Qualitative case review

Another aspect of the CBP was to have each of the three paediatric BIRP services identify up to four clients who were considered particularly challenging for qualitative review. It was expected that a thorough review of this select group of clients could 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 C) was undertaken with a clinician who knew the clients' challenging behaviours, treatments received and

background. Whenever convenient - sometimes before and sometimes after interview - the medical records and case notes of the qualitative review clients were examined to obtain background, injury details and also gain further understanding of any behavioural issues.

The information collected from each client was then written up into a case history, and each of the case histories then read to identify themes relating to the challenging behaviours of clients who sustain TBI.

It was anticipated in the paediatric arm of the CBP that the qualitative case review would be the primary source of information about comorbidity and challenging behaviour in children and adolescents<sup>5</sup>.

## RESULTS

To determine the prevalence, comorbidities and burden of challenging behaviours, a total of 188 BIRP paediatric clients met the study inclusion criteria. However, clinical informants for six BIRP clients did not return OBS-K forms, resulting in a final sample of 182 BIRP clients.

A summary of the demographic and clinical characteristics of the 182 paediatric clients included in the study can be viewed in Appendix D.

<sup>5</sup> In the adult arm of the CBP, mental health and drug and alcohol comorbidity was also assessed using specific validated quantitative measures.

**Table 2:** Prevalence of the nine types of challenging behaviour

	N	%
Inappropriate social behaviour	68	37.4
Verbal aggression	54	29.7
Adynamia/lack of initiation	28	15.4
Wandering/absconding	26	14.3
Physical aggression against others	26	14.3
Physical aggression against objects	23	12.6
Inappropriate sexual behaviour	21	11.5
Perseverative/repetitive behaviour	10	5.5
Physical aggression against self	7	3.8

## PREVALENCE OF CHALLENGING BEHAVIOURS

The prevalence of challenging behaviour was 51.1%, representing 93 paediatric community TBI clients from the three BIRP units who met criteria for challenging behaviour. This prevalence rate was based on clinician ratings using the OBS-K (see Table 1 on pages 12-13 for cut-off criteria for challenging behaviour).

### Prevalence of different types of challenging behaviour

Table 2 shows the prevalence of the nine different types of challenging behaviours assessed by the OBS-K. The three most common challenging behaviours were inappropriate social behaviour, verbal aggression and adynamia/lack of initiation. When considering all four types of aggressive behaviour assessed by the OBS together, 34.1% (n=62) children demonstrated challenging levels of aggressive behaviour.

## FACTORS RELATED TO CHALLENGING BEHAVIOUR PREVALENCE

Having established the prevalence of challenging behaviours, a series of analyses was undertaken to examine whether demographic and injury-related variables influenced the presence of challenging behaviours.

### Gender

Generally, the prevalence of challenging behaviour was not significantly related to the gender of children. Just over half of male (50.8%) and female (51.6%) paediatric clients demonstrated challenging behaviour. However, males (18.6%) were significantly more likely to demonstrate one type of challenging behaviour compared to females (7.5%), namely physical aggression against other people ( $p < 0.05$ ).

### 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 13.6 years for clients with challenging behaviour and 14.0 years for clients without challenging behaviour.

**Table 3:** Indigenous status and challenging behaviours

	Indigenous (%)	Non Indigenous (%)
Verbal aggression	77.8	30.8
Physical aggression against objects	44.4	12.0
Physical aggression against others	44.4	14.3
Wandering/absconding behaviour	55.6	13.5
Inappropriate social behaviour	77.8	36.1
Adynamia/lack of initiation	44.4	14.3

**Country of birth**

The rate of challenging behaviour was unrelated to whether children were born in Australia or overseas ( $p > 0.05$ ). For both groups half the clients demonstrated challenging behaviour.

**Indigenous status**

A significantly greater proportion of clients of Aboriginal or Torres Strait Islander background met criteria for challenging behaviour (88.9%) compared to non-indigenous clients (48.1%) ( $p < 0.05$ ). Clients of indigenous background also were significantly more likely to demonstrate specific types of challenging behaviour. Table 3 shows the specific challenging behaviours significantly more prevalent in children of indigenous background ( $p < 0.05$ ).

**Geographic location**

Clients resident in remote areas demonstrated the highest rate of challenging behaviour (75.0%) followed by urban (51.4%) and then regional clients (45.5%). However, the differences between these three geographical groups were not found to be statistically significant ( $p > 0.05$ ). At the level of individual behaviours none were significantly related to geographical location.

**Age at injury**

Age at injury was not related to challenging behaviour overall in paediatric clients ( $p > 0.05$ ). However, there was a significant relationship between age at injury and three specific types of challenging behaviour:

- Physical aggression against self: those demonstrating this behaviour at challenging levels had a median age of injury of 2.0 years compared to 7.2 years for those who did not demonstrate this behaviour at challenging levels
- Perseverative/repetitive behaviour: those demonstrating this behaviour at challenging levels had a median age of injury of 3.3 years compared to 7.2 years for those who did not demonstrate this behaviour at challenging levels
- Adynamia/lack of initiation: those demonstrating this behaviour at challenging levels had a median age of injury of 4.8 years compared to 7.3 years for those who did not demonstrate this behaviour at challenging levels

**Table 4:** Challenging behaviour (%) by PTA duration

	<24 hours (n=10)	2-6 days (n=12)	1-4 weeks (n=37)	1-6 months (n=18)
<b>All behaviours</b>	40.0	50.0	40.5	66.7
Verbal aggression	30.0	41.7	27.0	38.9
Physical aggression against objects	10.0	8.3	8.1	11.1
Physical aggression against self	0	0	5.4	0
Physical aggression against others	20.0	8.3	16.2	11.1
Inappropriate sexual behaviour	0	0	8.1	22.2
Perseverative/repetitive behaviour	0	0	1.0	2.0
Wandering/absconding	10.0	16.7	13.5	5.6
Inappropriate social behaviour	30.0	25.0	29.7	50.0
Adynamia/lack of initiation*	0	8.3	0	27.8

Note. \*p<0.05.

#### 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. However, it was related to the presence of perseverative/repetitive behaviour<sup>6</sup> (p<0.05):

- 4.5% (n=5) of those with MVA-related injuries
- 20.0% (n=4) of those with assault/non-accidental injuries
- 0% (n=0) of those with fall injuries
- 0% (n=0) of those with sport/leisure injuries
- 12.5% (n=1) of those with other TBI

Injury circumstance was not related to any other type of challenging behaviour.

#### Post-traumatic amnesia (PTA)

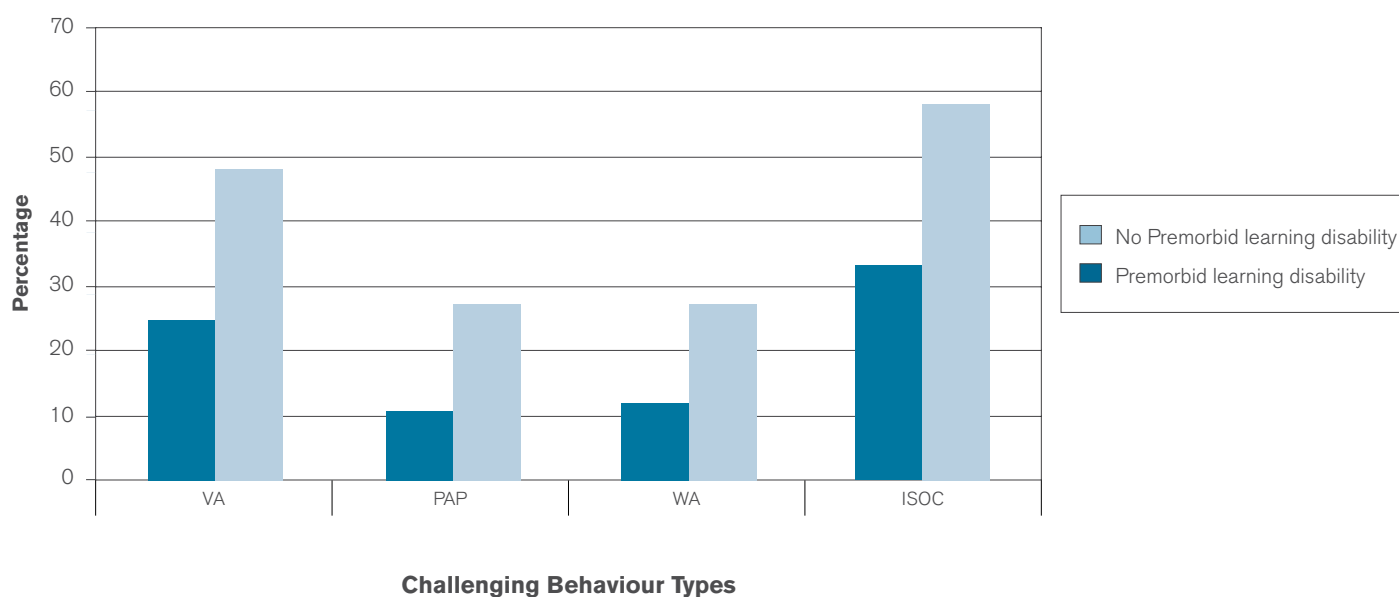
The rate of challenging behaviour was generally unrelated to length of PTA, with the exception of adynamia/lack of initiation (see Table 4). Table 4 shows a trend for clients with very long PTA (1-6 months) demonstrating higher rates of inappropriate sexual behaviour and inappropriate social behaviour compared to those clients with PTA of less than one month's duration. Comparison between these two PTA groups found a statistically significant difference in relation to inappropriate sexual behaviour (p<0.05).

<sup>6</sup> Caution needs to be taken in interpreting these results as numbers were small.

**Table 5:** Premorbid issues and challenging behaviour

	absent (%)	present (%)
Learning disability	46.6	69.7
Developmental disability	50.0	66.7
Psychiatric disturbance	48.5	83.3

**Figure 2:** Specific challenging behaviours and premorbid learning disability



VA=Verbal aggression; PAP=Physical aggression against other people; WA=Wandering/absconding behaviour; ISOC=Inappropriate social behaviour

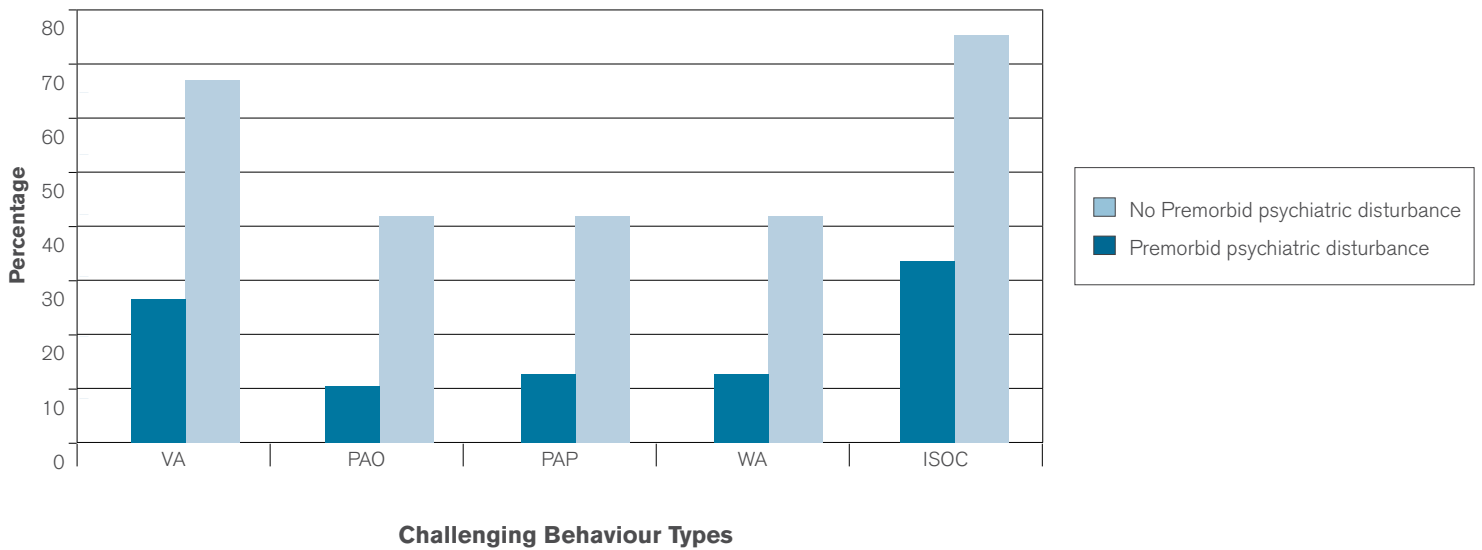
### Premorbid learning, disability and psychiatric disturbance

The rate of challenging behaviour for paediatric clients with and without premorbid learning disability, developmental disability or psychiatric disturbance can be seen in Table 5. Only premorbid learning disability and psychiatric disturbance were associated with a statistically significant greater prevalence of challenging behaviour ( $p < 0.05$ ).

Premorbid learning disability and psychiatric disturbance were significantly related to the prevalence of specific types of challenging behaviours, namely: verbal aggression, physical aggression against other people, wandering/absconding and inappropriate social behaviour ( $p < 0.05$ ). Premorbid psychiatric disturbance was also significantly related to physical aggression against objects ( $p < 0.05$ ). These results are detailed in Figure 2 and Figure 3. Premorbid history of developmental disability was not related to any type of challenging behaviour.



**Figure 3:** Specific challenging behaviours and premorbid psychiatric disturbance



VA=Verbal aggression; PAO=Physical aggression against objects; PAP=Physical aggression against other people; WA=Wandering/absconding behaviour; ISOC=Inappropriate social behaviour

## BURDEN OF CHALLENGING BEHAVIOURS

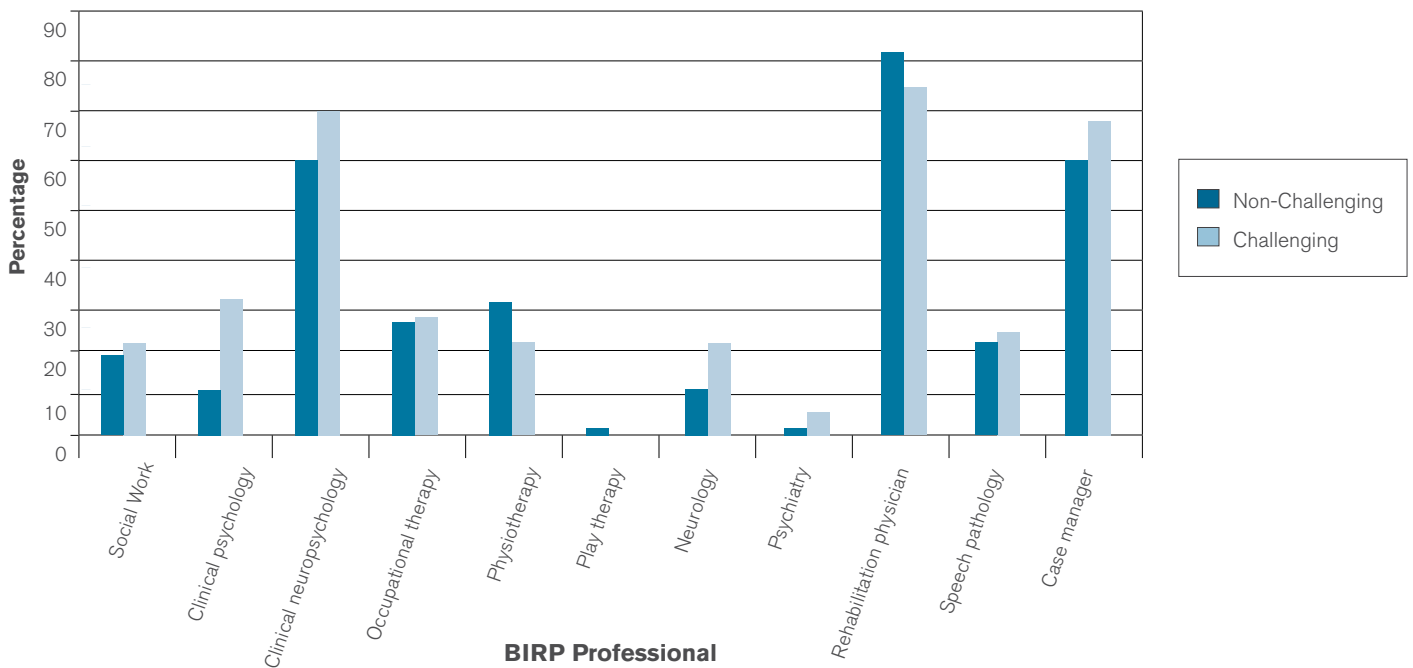
In the paediatric CBP, burden was evaluated in two ways. First, the relationship between challenging behaviour and issues with the family and child psychosocial situation was considered. Second, the demand that children and adolescents with challenging behaviour place on BIRP and non-BIRP services and the clinicians that work with them was evaluated.

### Family and client psychosocial issues and challenging behaviour

Clinical informants were asked to state if there were concerns with any of seven psychosocial situations (family, accommodation, health, education, employment, legal, loss of program/service) over the previous three months. It was found that a greater proportion of children with challenging behaviour were at greater risk of breakdown in their family and educational situation ( $p < 0.05$ ):

- 77.8% (n=14) of children with challenging behaviour experienced issues in their family situation compared to 48.2% (n=79) of children without challenging behaviour
- 71.7% (n=38) of children with challenging behaviour experienced issues with their educational situation compared to 42.6% (n=55) of children without challenging behaviour

**Figure 4: Challenging behaviour by BIRP services**



**BIRP service delivery to children with challenging behaviour**

The burden placed on BIRP to provide services to children and adolescents 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**

The median number of BIRP staff providing services to all children in the study was three (range=0-8). There was no 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 4). In particular:

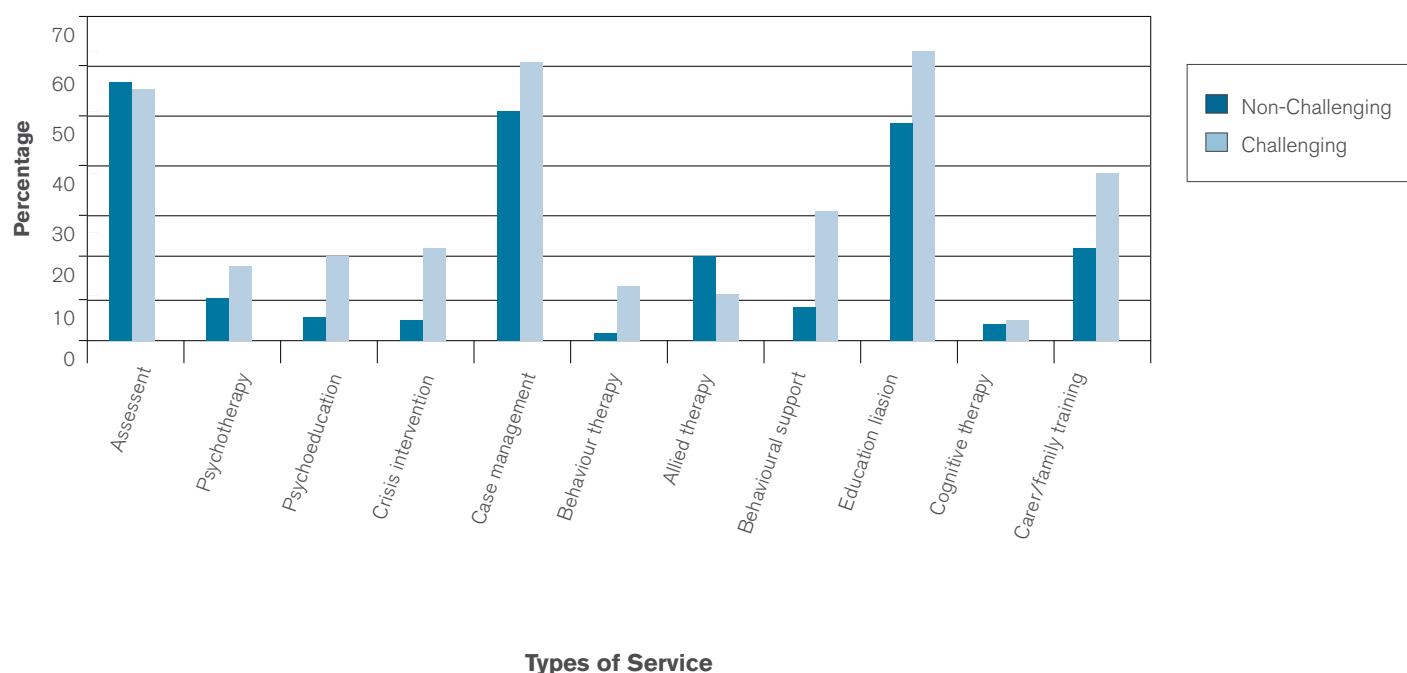
- 31 (33.3%) challenging clients were seen by a BIRP clinical psychologist compared to 11 (12.4%) clients without challenging behaviour
- 22 (23.7%) challenging clients were seen by a BIRP neurologist compared to 10 (11.2%) clients without challenging behaviour

The difference in rates of which challenging and non-challenging paediatric clients saw other BIRP professionals, depicted in Figure 4, was not statistically significant.

No difference was observed in the number of BIRP staff providing services to urban or regional/remote clients ( $p>0.05$ ). Each group had a median of three BIRP staff providing services to them. However, there was evidence that reception of services from specific BIRP professions depended on the geographical location of the client with challenging behaviour. Specifically, the statistically significant ( $p<0.05$ ) findings were:

- Occupational therapy services were received by 22.5% ( $n=16$ ) of urban clients with challenging behaviour compared to 55.6% ( $n=10$ ) of regional/remote clients with challenging behaviour.
- Neurology services were received by 16.9% ( $n=12$ ) of urban clients with challenging behaviour compared to 55.6% ( $n=10$ ) of regional/remote clients with challenging behaviour.
- Rehabilitation physician services were received by 81.7% ( $n=58$ ) of urban clients with challenging behaviour compared to 50.0% ( $n=9$ ) of regional/remote clients with challenging behaviour.
- Case management services were received by 76.1% ( $n=54$ ) of urban clients with challenging behaviour compared to 33.3% ( $n=6$ ) of regional/remote clients with challenging behaviour.

**Figure 5: Challenging behaviour by clinical informant services**



These results reveal that paediatric clients in more isolated parts of the state were less likely to receive service from case managers and rehabilitation physicians compared to urban paediatric clients. In the adult CBP it was also found that rehabilitation physicians were less likely to provide services to more geographically isolated clients compared to their urban counterparts, but BIRP was more likely to provide remote adult clients a case management model of care. Together, findings from the adult and paediatric CBP reveal a disparity of service delivery based on age.

Somewhat unexpectedly, it was found that two BIRP services were more likely to be provided to regional/remote challenging behaviour children compared to their urban counterparts. Urban clients were less likely to receive services from neurologists than remote/regional clients. However, this was thought to reflect the fact that urban clients' neurological care was usually met via the rehabilitation physician, which was not available to more geographically isolated clients. It is also important to note that it is only at Kaleidoscope, Newcastle that neurologists provide brain injury services. In regards to occupational therapy, Kaleidoscope reviewed their clients who contributed to the effect of more occupational therapy services being provided to regional/remote compared to urban clients. This post-hoc analysis uncovered that regional/remote clients were more likely to have insurance coverage for injuries, suggesting the possibility of insufficient level of service delivery for paediatric occupational therapy services for clients who were not compensable.

#### Services provided by BIRP to clients

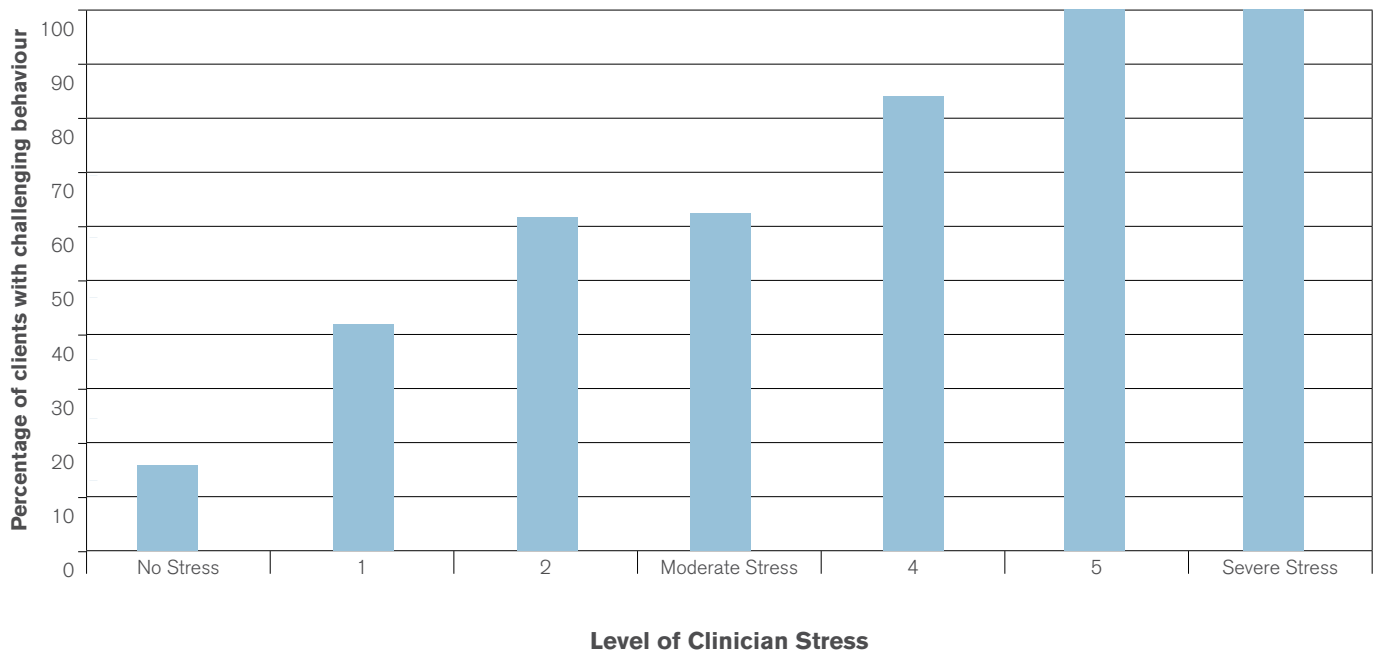
BIRP provided clients with challenging behaviours significantly more services compared to clients without challenging behaviour, including psycho-education, crisis intervention, behaviour therapy and behavioural support ( $p < 0.05$ ; see Figure 5). There was a non-significant trend for clients with challenging behaviour to receive more carer/family training and education liaison compared to clients without challenging behaviour ( $p < 0.10$ ).

BIRP provided assessment, psychotherapy or counselling, case management, allied therapy (occupational, physical or speech therapy) and cognitive therapy to an equivalent number of challenging and non-challenging paediatric clients.

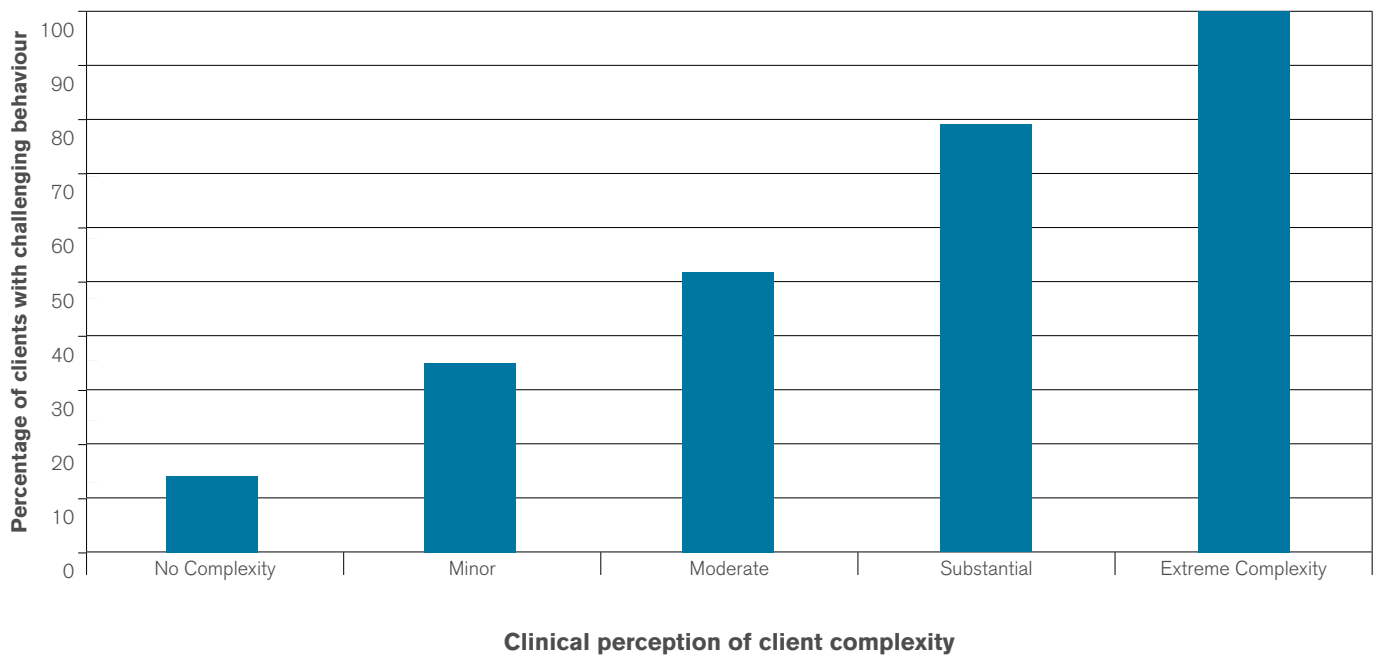
Clients in urban locations received a median of three BIRP services whereas clients in regional/remote parts of the state received a median of two BIRP services. This difference was statistically significant ( $p < 0.05$ ). Specifically, the following services were more likely to be received by urban clients with challenging behaviour:

- Psychotherapy/counselling services were provided to 23.9% ( $n = 17$ ) of urban challenging behaviour clients compared to nil regional/remote challenging behaviour clients.
- Crisis intervention services were provided to 29.6% ( $n = 21$ ) of urban challenging behaviour clients compared to nil regional/remote challenging behaviour clients.
- Case management services were provided to 73.2% ( $n = 52$ ) of urban challenging behaviour clients compared to 16.7% ( $n = 3$ ) of regional/remote challenging behaviour clients.
- Behavioural support services were provided to 35.2% ( $n = 25$ ) of urban challenging behaviour clients compared to 11.1% ( $n = 2$ ) of regional/remote challenging behaviour clients.

**Figure 6:** Challenging behaviour and clinician stress



**Figure 7:** Challenging behaviour and client complexity

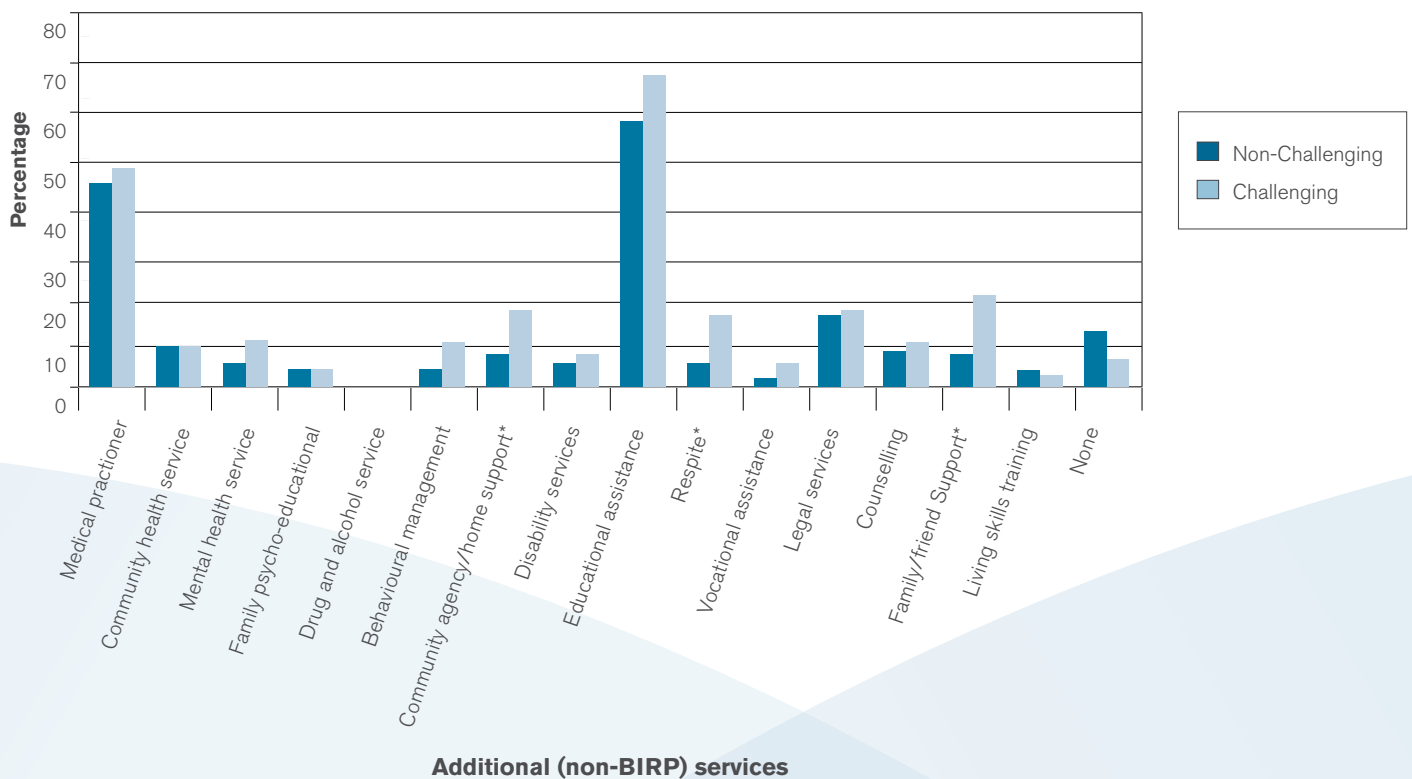


### Contribution of challenging behaviour to clinical informant stress

There was a statistically significant relationship between challenging behaviour and clinical informant experience of stress working with children (see Figure 6). All children and adolescents rated at the two most extreme levels of stress had challenging behaviour.

Similarly, there was a significant relationship between challenging behaviour and clinical informant perception of client complexity (see Figure 7). Clients that were rated at least moderately complex were more likely to have challenging behaviour. All clients that were rated extremely complex had challenging behaviour.

**Figure 8: Challenging behaviour by additional (non-BIRP) services**



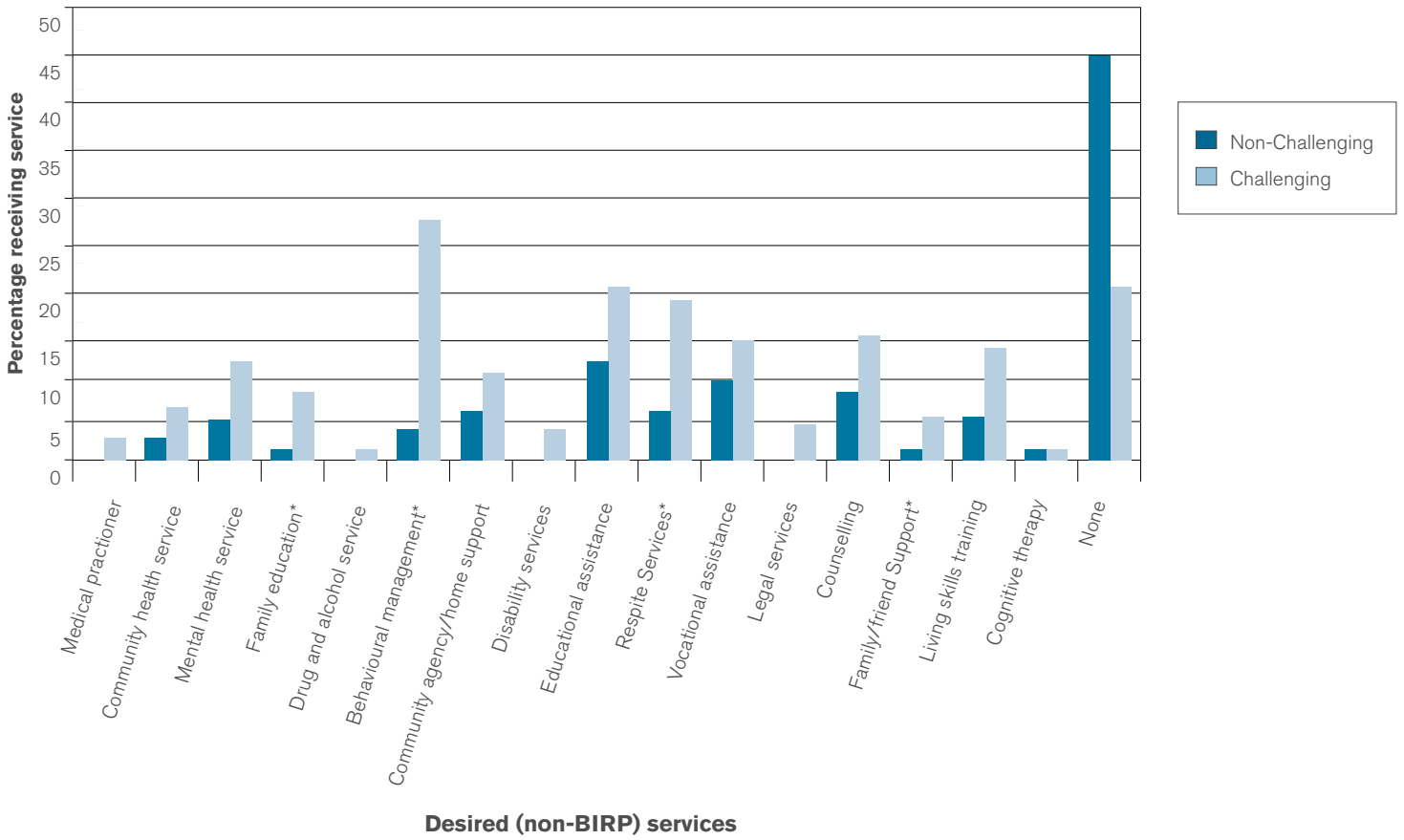
### ADDITIONAL (NON-BIRP) SERVICE DELIVERY TO CLIENTS WITH CHALLENGING BEHAVIOUR

#### Received and desired non-BIRP services

Overall, children with challenging behaviour did not receive significantly more non-BIRP services than children without challenging behaviours ( $p > 0.05$ ). However, there were specific additional (non-BIRP) services that challenging behaviour clients utilised more than non-challenging behaviour clients including community agency/home support, respite and family/friend support ( $p < 0.05$ ). This is illustrated (\*) in Figure 8.

The following non-BIRP services were received by an equivalent proportion of challenging and non-challenging clients: medical practitioner, community health, mental health, family psycho-education, behavioural management, disability, educational assistance, vocational assistance, legal, counselling, living skills training, speech therapy and occupational therapy.

**Figure 9: Challenging behaviour and desired (non-BIRP) services**



Clients with challenging behaviour were more likely to have more unmet need (i.e. services desired but not provided) as identified by their clinical informants, compared to clients without challenging behaviour. This was a statistically significant finding for three services: family education, behavioural management and respite services. This is shown (\*) in Figure 9.

The following non-BIRP services were desired for an equivalent proportion of challenging and non-challenging clients: medical practitioner, community health, mental health, drug and alcohol, community agency/home support, disability, education assistance, vocational assistance, legal, counselling, family/friend support, living skills training, case management and cognitive therapy.

Geographical location was not found to be related to the likelihood of non-BIRP services being received ( $p > 0.05$ ). An equivalent proportion of challenging clients in urban and regional/remote areas received non-BIRP services. However, there was a trend for greater unmet need regarding family-based services for clients with challenging behaviour in more isolated geographic areas ( $p = 0.05$ ):

- 5.6% ( $n = 4$ ) of urban clients with challenging behaviour had family education desired for them compared to 22.2% ( $n = 4$ ) of regional/remote clients with challenging behaviour
- 2.8% ( $n = 2$ ) of urban clients with challenging behaviour had family/friend support desired for them compared to 16.7% ( $n = 3$ ) of regional/remote clients with challenging behaviour

There was one area where urban clients demonstrated greater unmet need compared to regional/remote clients, namely vocational assistance. Whilst no challenging behaviour clients in regional/remote areas had vocational assistance desired for them, 19.7% ( $n = 14$ ) of urban clients with challenging behaviour neither received nor accessed vocational assistance services despite it being desired for them ( $p < 0.05$ ).

## QUALITATIVE CASE REVIEW

Ten child and/or adolescent histories were undertaken for the case review. This review led to the identification of 24 themes pertinent to understanding the challenging behaviour seen in children and adolescents 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. It was found that subgroups or clusters of themes could be identified<sup>7</sup> (see Figure 10). Four of these clusters were grouped as issues pertaining to the development and maintenance of challenging behaviours; another set of themes reflected the consequences of challenging behaviour. A summary of each of the clusters of themes is presented below.

### Family adjustment issues

There was variability in the capacity of families to respond to challenging behaviours encountered. Higher functioning families were able to take on board strategies provided to them from the BIRS and make reasoned decisions about how to appropriately respond as the child developed, or as issues arose that changed the nature or severity of behaviours. In contrast, families with limited education, independent problem-solving capacity and positive parenting skills struggled to implement strategies despite receiving education from the BIRS. It is noteworthy this sometimes resulted from a lack of engagement by families with the BIRS or the difficulty for families in integrating the model of behavioural management put to them with their own cultural beliefs about parenting.

### Child characteristics

Both pre- and post-injury characteristics of children influenced the nature of challenging behaviour. Premorbid behavioural and learning difficulties were exacerbated as a result of the TBI. A number of factors often interacted to affect children's behaviour post-injury including: cognitive impairments and/or disability; fatigue; and lack of insight. This last factor affected children's ability to recognise the need to regulate their behaviour or to engage with rehabilitation providers who aimed to decrease challenging behaviours and increase positive behaviours. A unique feature in this younger population was finding that the nature of challenging behaviours could change during the course of development. Adolescence was associated with an increase in oppositional behaviours and also the emergence of sexually inappropriate behaviour.

### Environmental factors (non-family)

The environment in which children with TBI found themselves was a critical factor influencing the display of challenging behaviour. Challenging behaviours were often encountered in environments that lacked structure and supports to cater for children's cognitive impairments and learning disabilities. Moreover, environments that failed to be guided and/or implement BIRS-suggested management approaches often resulted in the frequency and intensity of behavioural problems increasing over time, resulting in catastrophic consequences in some cases such as serious physical injury. Clients who displayed challenging behaviour were also influenced by peers who encouraged them. School was the one environment outside the family home where challenging behaviours were often encountered. However, there were also examples where these behaviours occurred in other public places (e.g. swimming pools; shopping centres). The lack of access to important psychological services for behavioural management because of the geographical isolation of clients was also shown to be a complication in the case review.

### Medical issues

Although rare, there were isolated examples showing that deteriorating medical conditions, such as a seizure or epileptic disorder, can be an underlying cause of poor behaviour. Drug and alcohol issues also affected children's behaviour and their level of engagement with services that tried to provide assistance. Often medications for behavioural management were refused by parents who did not like the side-effects of the drugs or were philosophically opposed to such treatments. However, there were cases where drugs, when they were taken, did assist in managing challenging behaviour.

### Consequences of challenging behaviour

There was a variety of consequences resulting from children's challenging behaviours. Behaviours interfered with clients achieving important developmental milestones such as becoming independent in self-care and social interactions. These children were at increased risk of falling behind their peers in learning as they were disengaged with the educational system. Clients were also prone to be excluded from avenues of participation because of challenging behaviours (e.g. refused entry to shops, swimming pools and loss of respite placement). The challenging behaviours demonstrated by clients led to increased stress and tension within families, resulting in intra-family conflict and issues with mental health and adjustment, which further diminished the capacity of families to respond to challenging behaviours.

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<sup>7</sup> It is important to note that clusters simply provided a means of organising the 24 themes. This was done by considering the general essence conveyed by the theme. Sometimes there were specific aspects of a theme that may have had a closer relationship with a different cluster to which it was allocated, emphasising that the clusters are not mutually exclusive.

**Figure 10:** Themes and thematic clusters identified from qualitative case review





# CONCLUSION

The aim of this study was to collect data on prevalence and burden to inform the development of a model of care for paediatric TBI clients who have or are at risk of developing challenging behaviours. This model of care would then be integrated into the existing model of service delivery used by BIRP, which represents the largest brain injury service provider in NSW.

BIRP aims to put in place the necessary supports and rehabilitation options so that children and adults can live successfully within their community and family structures. This is reflected in the BIRP mission statement, which outlines the following objectives:

- To provide assessment, rehabilitation and community support services for the present and future needs of children, young people and adults with traumatic brain injuries and their families
- To establish and develop specific relationship programs to enable maximum reintegration of people with traumatic brain injury into the community in line with the needs and preferences of each individual
- To provide a goal-directed individual management system for the client and to minimise dependency and maximise function
- To 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 injuries and their families
- To assist people with traumatic brain injury and their families through advice, information, discussion and counselling during medical, rehabilitation and community support phases
- To undertake research and education about traumatic brain injury
- To increase community awareness of the particular problems faced by the person with traumatic brain injury and his or her family
- To provide consultation and support to other service providers in the area of traumatic brain injury management.

The 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 paediatric CBP identified eight key principles to be integrated into the BIRP model of service delivery so that better outcomes could be achieved for clients with or at risk of developing challenging behaviour. Each of these principles and the paediatric data supporting them are presented below.

## 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 paediatric BIRP cohort; 51% of BIRP paediatric clients with TBI met the study criteria for challenging behaviour. The two most prevalent types of challenging behaviour in children were socially inappropriate behaviour followed by aggression, present in 37% and 34% of clients respectively. Substantially fewer children demonstrated other types of challenging behaviour including the next most prevalent of the challenging behaviours, adynamia/lack of initiation, which was prevalent in 15% of children with TBI.

The qualitative paediatric case review found that maladaptive behaviours developed soon after children sustained their TBI, but families endured significant stress and despair in relation to these behaviours before seeking assistance and referral to BIRP services. These cases were difficult for BIRP to treat as the behaviours, despite the relatively few years they may have been present, had become entrenched and family/carer habitual responses and/or behaviour-maintaining environments needed to be undone. It is noteworthy that in longitudinal studies spanning up to five years, challenging behaviour has been shown to become increasingly prevalent as children become older, especially for severe TBI (Catroppa et al., 2008; Schwartz et al., 2003). This is particularly relevant as severe TBI makes up over 85% of the paediatric BIRP caseload.

The current study also found that children may be more likely to experience certain types of challenging behaviours if their injuries occurred before school age. These behaviours included physical aggression against self, perseverative/repetitive behaviour and adynamia/lack of initiation.

The above 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 this regard BIRP needs to be geared to respond to the greater proportion of children presenting with socially inappropriate behaviours and aggressive behaviours. In addition BIRP needs to ensure the ongoing monitoring of families who have children with challenging behaviour so that effective 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 paediatric 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:**

BIRP needs to increase the provision of behaviour management programs (e.g. formal social skills retraining and anger management programs) to respond to the high prevalence of socially inappropriate and aggressive challenging behaviours after childhood TBI.

**Recommendation 3:**

BIRP services need additional resources to be able to adequately evaluate the effectiveness/outcomes of behavioural management plans so they can promptly respond 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.

**Recommendation 5:**

BIRP services need to strengthen and maintain their relationship with community referral and support networks to improve access for children and families dealing with challenging behaviour.

**PRINCIPLE 2:**

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

The qualitative case review found that cognitive impairment and disability contributed to the development and maintenance of challenging behaviours. It is the deficits in and/or lack of ongoing development of executive cognitive abilities, which include self-monitoring, impulse control, emotional processing, abstraction, conceptual reasoning, feedback utilisation and problem-solving, that contribute to a child's inability to regulate their behaviour after TBI (Levin & Hanten, 2005). Moreover, the qualitative review found that increased fatigue conspired with cognitive deficits to further reduce children's level of frustration tolerance, exacerbating challenging behaviour episodes.

The greater level of impairment and disability experienced by children with challenging behaviour was expected to give rise to greater service need and utilisation. Indeed, it was found that a greater proportion of children with challenging behaviour accessed clinical psychologists than children without challenging behaviour, and although there was no difference in the rates at which challenging and non-challenging children accessed specialist rehabilitation, case management or clinical neuropsychological services, a high proportion of both groups was found to access these professions (60-80%). In contrast, other BIRP professionals (e.g. occupational therapy, speech pathology, etc) provided a relatively low rate of service to children with or without challenging behaviour.

BIRP needs to reappraise the delivery of therapy services to clients who demonstrate, or who are at risk of showing, challenging behaviours. The results of the CBP suggest that challenging behaviour clients may not be receiving BIRP services they need. The following is recommended:

**Recommendation 6:**

BIRP needs to ensure a consistent and multi-disciplinary approach to the management of clients where the psychosocial environment and/or cognitive, language and physical functioning of clients are recognised as the context of challenging behaviours.

**Recommendation 7:**

BIRP services need to ensure the availability of skilled staff as part of a multi-disciplinary team to provide behavioural management services that consider the developmental, family, educational and community context in which these behaviours occur.

**PRINCIPLE 3:**

## Clients require adequate level of long-term care, support and environmental modification

The project found that 78% of children with challenging behaviour experienced breakdown in their family situation compared to 48% of children without challenging behaviour. The qualitative case review found that the home environment was particularly important in the delivery of needed care and support services. The review of these cases 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 that whilst there was proportionally more community agency/home support services, support from family/friends and respite services provided to families with a child exhibiting challenging behaviours, there was also greater unmet need for services that support families.

Specifically, family education, behaviour management and respite services were desired but not accessed or received by a greater proportion of families with a child with challenging behaviour compared to families not burdened by such behaviours.

Another important area where children need support after TBI is at school. The qualitative review found that cognitive impairments, behavioural dysregulation and emotional adjustment issues resulting from TBI interfered with children's learning and educational achievement. Over 60% of children in the study sample received educational assistance. Despite this high uptake, 72% of children with challenging behaviour experienced a breakdown in their educational situation compared to 43% of children without challenging behaviour. Unmet need for educational assistance services was one reason for this high rate of breakdown. Twenty percent and 14 percent of challenging and non-challenging children respectively had educational assistance services desired for them that were not provided.

Reasons for the lack of educational support identified in the qualitative review included insufficient level of funding (e.g. funding available for shared but not one-to-one teacher's aide; children not qualifying for funding); delays in schools making applications for learning support; educational institutions being completely unaware of a student's TBI status and resulting difficulties; and the belief and attitudes of some staff that interfered with implementation of recommended behavioural management and learning support approaches recommended by the BIRP services.

BIRP services need to reduce the unmet need of clients with challenging behaviour or those at risk of demonstrating it. 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. More also needs to be done to provide the necessary school support for children after TBI to maximise their developmental and academic potential. The following is recommended:

**Recommendation 8:**

A network of BIRP paediatric co-ordinators is needed to facilitate access to needed care and support services within the local community.

**Recommendation 9:**

There is a need to advocate for increased in-home services so that families can sustain their role in providing care and support to children and adolescents with TBI.

**Recommendation 10:**

BIRP needs to be better equipped to provide families with home-based interventions so the families are enabled to provide the necessary supports for children.

**Recommendation 11:**

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

**Recommendation 12:**

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

**Recommendation 13:**

BIRP needs to undertake comprehensive assessment of families' adaptive skills and capacity to provide positive parenting to their child post-TBI.

**Recommendation 14:**

BIRD should develop standard challenging behaviour education program(s), e.g. workshop(s), for family and ancillary services that care for paediatric clients with TBI.

**Recommendation 15:**

There is a need to increase the range of respite services available to strengthen the capacity of families to manage children with challenging behaviour by improving access to existing respite services and developing new approaches to respite.

**Recommendation 16:**

BIRD needs to liaise with the BIA to explore options about advocacy for improved access to appropriate services (e.g. emergency respite; educational support; family support) to meet the needs of children with TBI and maintain a positive family environment.

**Recommendation 17:**

BIRD needs to promote state-wide education programs for teachers and educational authorities, government and non-government alike, to increase their awareness of issues relevant to children with TBI and how best to support them so their learning is not disadvantaged.

**Recommendation 18:**

BIRD needs to advocate for access to a functional assessment-based approach to funding educational support needs that considers the behavioural, emotional and executive impairments (not only IQ) that impact on learning and day-to-day functioning of children with TBI, so as to help ensure the delivery of adequate levels of educational support and teacher's aide hours.

**Recommendation 19:**

BIRD needs to advocate for an expansion of learning support teams so children with TBI can have access to special classroom resources to maximise their learning and reduce occurrence of challenging behaviour.

#### PRINCIPLE 4:

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

A number of factors were demonstrated to be related to the presence of challenging behaviours. There was some evidence that demographic characteristics such as gender (males) and indigenous status (Aboriginal/Torres Strait Islander) were related to increased rates of specific types of challenging behaviour. Children with premorbid developmental learning issues and psychiatric disturbance had a significantly higher prevalence of challenging behaviour generally. Moreover, the qualitative case review showed many examples where behaviour dysregulation was present prior to children sustaining their injuries, supporting the extant evidence that premorbid behaviour problems contribute to the severity of behavioural disturbance seen after brain injury (Schwartz et al., 2003).

The current study did not find strong evidence for injury-related factors to be related to challenging behaviour prevalence in children. The small sample size when children were stratified on the basis of different types of injury or severity of injury may partially have contributed to finding few statistically significant differences. It is noteworthy that others have also found that the prevalence of childhood behaviour problems do not appear to vary as a function of injury severity or injury circumstance (Eisenberg, 1990; Fletcher et al., 1996; Ganesalingam et al, 2006; Hawley, 2003). However, there is evidence for an increase in challenging behaviour prevalence over time in children with severe TBI. This may reflect the lack of maturation of expected cognitive-behavioural regulation processes as children with severe TBI develop, an increased stress reaction in children with severe TBI as greater environmental expectations are placed on them as they get older, despite their cognitive impairments, or, as is more likely the case, a combination of these two mechanisms.

The qualitative review showed how medical comorbidities contributed and compounded challenging behaviours observed in children with TBI. In one of the paediatric case histories, post-traumatic seizures were found to affect behaviour. The anomalous electrical, epileptic activity in the frontal regions of this child's brain were thought to be interacting with areas already affected by the TBI, resulting in an exacerbation of his behavioural disturbance. Indeed, initiation of anti-epileptic drug therapy resulted in reduced incidences of challenging behaviour. Other medical comorbidities that were known to be impacting on children's behaviour included adolescent drug and alcohol use, but more commonly mental health issues, particularly childhood anxiety and depression. The CBP found that children with or without challenging behaviour were generally well serviced for their medical needs, except in the case of mental health problems where there was relatively high

unmet need for services for children with challenging behaviour. Approximately 13% of children with challenging behaviour had their mental health needs unmet compared to only 5% of children without challenging behaviour.

In addition to the above child specific characteristics, some children were known to live in very complex psychosocial environments where parents and siblings struggled with drug, alcohol and/or mental health issues of their own, resulting in environments for children that were disorganised at best but more commonly chaotic. In these circumstances parents were neglectful or completely absent as care givers and at best were simply overwhelmed by the multitude of psychosocial stressors, making them incapable of responding to the needs of their child with TBI and provide a positive, nurturing environment. Another important factor affecting behaviour was the cultural identities and attitudes of families and the communities in which they lived. For example, authoritarian parenting styles where punishment was the main means of responding to behaviour were often found not to be effective and were perceived as unfair by children.

The above findings reveal the myriad of factors that contribute to and maintain challenging behaviour, thereby emphasising the need to take a whole-of-client approach in behavioural management. However, paediatric BIRP services were shown to have difficulties in implementing such an approach when children lacked insight into their difficulties and lacked willingness to engage with services. Parents too were sometimes unwilling to prioritise the need for services despite their complaints about challenging behaviours.

Although rare, the qualitative review also found examples where services excluded clients because of instances of severe destructive and impulsive, dangerous behaviours. There also were non-BIRP services that provided minimal follow-up of clients, or which were reluctant to review a client's situation when it was critical in terms of trying to manage a client's behaviour.

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, and strategies need to be developed to ensure that children's need for services to tackle these issues are met. The following is recommended:

#### **Recommendation 20:**

BIRD needs to support the implementation of protocols for assessment of premorbid and current issues which will aid in the assessment of risk of clients developing challenging behaviour. This should include systematic assessment of premorbid behaviour, mental health and medical comorbidity, family functioning, cultural identity, developmental levels and level of impairment and disability.

**Recommendation 21:**

BIRP services need to identify the indigenous status of clients so they can involve and collaborate with the Aboriginal Health Service and other indigenous service providers when working with indigenous TBI clients.

**Recommendation 22:**

BIRP services need to routinely assess the mental health status of paediatric clients, including depression, anxiety and emotional adjustment, and make referrals to appropriate mental health services as soon as possible.

**Recommendation 23:**

BIRP services need to liaise with multicultural health services when engaging with clients from culturally and linguistically diverse backgrounds.

**Recommendation 24:**

BIRP staff need to advocate for access and support for children in non-BIRP health and other required services (e.g. respite, behavioural support services, family and parenting support, community trained staff).

**Recommendation 25:**

BIRD needs to develop education programs that will support other services that come into contact with paediatric TBI clients to increase their awareness of TBI issues and how to be able to successfully provide services to paediatric TBI clients.

**PRINCIPLE 5:**

## There is a need for equitable access to all services throughout NSW based on need

The CBP documented a trend for challenging behaviour to be more prevalent in children living in remote parts of NSW (75%) compared to urban and regional locations (52% and 46% respectively). Despite the very high prevalence of challenging behaviour in remote geographical locations, children in more isolated parts of the state generally received fewer BIRP services. For instance, rehabilitation specialist services were provided to 82% of urban clients compared to only 50% of regional/remote clients with challenging behaviour, while only one-third of geographically isolated children with challenging behaviour received case management services compared to three-quarters of their urban counterparts. This result contrasts with that found in the adult CBP where case management services filled the gap of specific professional BIRP services that were lacking (ACI, 2011). It appears that geographically isolated children with challenging behaviour fare worse than adults in terms of BIRP service provision.

There were two services that BIRP did not provide to any challenging behaviour paediatric clients in regional/remote areas. These were psychotherapy/counselling and crisis intervention, which were provided to 23% and 30% of urban children with challenging behaviour. Behaviour support was also provided sparingly by BIRP in more isolated parts of the state. Only two of 18 clients with challenging behaviour in regional/remote areas received behavioural support services, compared to 35% in urban geographic locations. There was a suggestion that BIRP services in more remote parts of the state could be made more accessible when there were third-party purchases of the services.

Interestingly, there was greater unmet need for vocational assistance among children with challenging behaviour living in urban locations than regional/remote locations. Indeed, no children with challenging behaviour in more isolated parts of the state were thought to have unmet need for vocational assistance services, compared to 20% of their urban counterparts. This is unusual and may indicate that vocational rehabilitation services are not even contemplated for more geographically isolated children.

BIRP services need to develop their model of care so that they are able to adequately deliver services to paediatric clients living in more remote parts of the state, redressing the current inequity based on geography and age. The following is recommended:

**Recommendation 26:**

BIRP services that cater for more geographically isolated clients need to have the option of providing behavioural services for children and/or for there to be an increase in resources to enable staff from these services to travel to remote areas.

**Recommendation 27:**

All BIRP services need an appropriate number and skill mix of case managers and/or social workers to manage family and ancillary carer issues.

**Recommendation 28:**

There is a need to increase psychological services within paediatric BIRP services to deal with the presentation of emotional and behavioural issues after TBI.

**Recommendation 29:**

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

**Recommendation 30:**

BIRP needs to increase its capacity to provide a network of rehabilitation coordinators to support staff in other services in more geographically isolated areas where there is currently minimal or no infrastructure support for children with TBI and their families.

**Recommendation 31:**

BIRD needs to liaise with ADHC and other relevant service providers to explore options about improving access to needed services for children with TBI in remote/regional parts of the state.

**Recommendation 32:**

BIRD to explore with BIRP services barriers to why children with challenging behaviour in regional/remote areas are not receiving the support required to access vocational assistance.

**PRINCIPLE 6:**

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

Along with assessment, education liaison was the most frequently provided BIRP service for children with challenging behaviour. Sixty-four percent of children with challenging behaviour received this service. The purpose of this service is to provide education about TBI, the specific impairments and disabilities that would impact on their learning and psychosocial development and to assist with the implementations of recommendations, strategies and support services to maximise each child's potential. It was found that BIRP would meet with school personnel regularly over the course of a school year and at important transition points in the educational curriculum as well as at times of crises. However, the qualitative case review uncovered problems in the existing communication pathways used by BIRP when liaising with educational institutions. The qualitative review revealed situations where different school personnel attended meetings with BIRP, requiring BIRP to educate and orient new people on the needs of a child. Also, there was sometimes a lack of consistent handover to other staff members about a child's behavioural and learning support needs. The following is recommended:

**Recommendation 33:**

Special school counsellor (brain injury) roles need to be expanded (multiple and full-time) so there is a consistently available interface between rehabilitation and education to improve learning outcomes.

**Recommendation 34:**

There is a need to develop well defined and consistent communication pathways between BIRP services and schools (through learning support teams or equivalent structures in independent and Catholic schools) regarding individual children with TBI.

**PRINCIPLE 7:**

## Specialised assessment and management is required for challenging behaviours in the TBI paediatric population

When working with children comprehensive assessment of the individual child or adolescent, their family and school setting is crucial to the choice of intervention. A wide range of psychological treatments may be appropriate and will depend on the problem. The qualitative case review found that although implementation of operant conditioning principles as well as positive behavioural support were utilised this was done in a broader context of attempting to address the different needs of children and adolescents as they progress through different developmental stages, as well the psychosocial environment of the child and any cognitive, emotional and physical deficits they may have as a result of TBI (see also Principle 4).

Evidenced-based behavioural interventions for children and adolescents within the general clinical population focus on family interventions that include parent training and support. These programs have a theoretical background not only in the principles of social learning theory and operant conditioning but also in attachment theory. There is limited research on the use of these programs with children with disabilities and particularly with TBI although there is an emerging literature (Hudson, Cameron, & Matthews, 2008; Wade et al., 2008; Wade et al., 2011; Warschusky, Kewman & Kay, 1999). In general, a manualised approach is rarely appropriate because of the complex interacting factors. Therefore specialised staff are required for the assessment and treatment of challenging behaviour in this population. The following is recommended:

**Recommendation 35:**

BIRP needs to maintain capacity and have adequate availability of skilled staff in metropolitan and rural NSW. Skilled staff will consider a range of behavioural management approaches for intervention and integrate them in the family and developmental context in which the behaviours occur.

**PRINCIPLE 8:**

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

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., 2007) 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 36:**

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

**Recommendation 37:**

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

**Recommendation 38:**

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

**Recommendation 39:**

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

**Recommendation 40:**

The capacity of disability and generic leisure and recreation service providers to accommodate children with TBI and challenging behaviour should be increased.

**Recommendation 41:**

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

**Recommendation 42:**

BIRP staff need to be able to access the range of social technologies available for undertaking of therapies that will promote clients developing and sustaining social networks.

**Recommendation 43:**

To improve the current paediatric BIRP model of care a Behaviour Support and Development Service (BSDS) is required that would initially focus efforts in rural and remote NSW where there is currently little or no behavioural management support services.

**Implementation of Principles and Recommendations**

The establishment of a Behaviour Support and Development Service (BSDS) would be the most practical and efficient method of ensuring the application of the above eight principles and developed recommendations across the BIRP network.

The BSDS would need to focus their service delivery in more remote parts of the state where there is currently little or no behavioural management support or interagency links with non-BIRP services. The consultancy may have a greater education and training role in BIRP units that currently have inadequate psychological support. Moreover, the proposed service will need to be able to flexibly provide services to a wide age range of clients including children and adolescents where the variability of behavioural presentations will be determined by developmental, attachment, family and educational issues. Specifically, the BSDS would have the following objectives:

- Comprehensive assessment of needs of challenging behaviour clients and their families, and of clients at risk of developing challenging behaviour
- Development of comprehensive family and community-based interventions for challenging behaviours
- Provision of support to families, ancillary carers and BIRP staff in implementing behavioural interventions
- Education of knowledge and skills required by families/ancillary carers; and BIRP about TBI and challenging behaviour
- Education and support of other providers, including educational institutions, respite services and other health organisations, so they can initiate and maintain needed services to clients with TBI
- Develop and support participation opportunities for clients with, or at risk of developing, challenging behaviour.

It will be essential for the BSDS 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 clients 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. teachers, case managers, therapists, rehabilitation specialists and psychiatrists.

**Table 6:** Areas targeted by recommendations

	BIRD	BIRP	Non-BIRP
<b>Service delivery</b>	14, 17, 25	1, 2, 3, 4, 5, 6, 7, 9, 10, 13, 15, 21, 22, 23, 24, 26, 35, 36, 37, 38, 39	18, 19, 40, 41
<b>Workforce</b>			
- Resources	43	8, 27, 28, 29, 30	33
- Training			11
<b>Policy</b>	16, 20, 31, 32	34, 42	12

Table 6 provides an organised structure of the recommendations arising from this project, including the establishment of a Behaviour Support and Development Service (recommendation 43). This table 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 (including resources and training) and Policy.

## SUMMARY

This study established the prevalence and burden of challenging behaviours in BIRP paediatric clients with TBI. These results informed the development of eight principles to guide clinical practice and 43 recommendations for changes or enhancement to the existing model of service delivery for children with or at risk of demonstrating challenging behaviour. It was suggested that 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

## EVIDENCE OF THE RELIABILITY AND VALIDITY OF THE OBS-K

As the OBS-K is a new instrument developed for the current study, there was no available information on its reliability and validity. Convenience samples from the three paediatric BIRP services were used to obtain OBS-K clinician ratings for evaluation of intra- and inter-rater reliability.

To evaluate intra-rater (or test-retest) reliability, clinicians completed a baseline OBS-K rating and then re-rated the same clients on the OBS-K four weeks later. Twenty-five valid re-ratings were obtained. As with the OBS (Kelly et al., 2006), three summary scores of behavioural severity were calculated on the OBS-K: the cluster, total levels, and clinical-weighted severity scores (see box below for scoring instructions).

**The cluster score is obtained by identifying the number of behavioural domains (out of a total of 9) in which a client's behaviour was rated (i.e. the nine domains correspond to verbal aggression, three forms of physical aggression, inappropriate sexual behaviour, perseverative/repetitive behaviour, wandering/absconding behaviour, inappropriate social behaviour and adynamia/lack of initiation).**

**The total levels score is computed by tallying each of the levels endorsed for the client across all 9 behavioural domains (out of a total of 35). For example, if a client was rated as demonstrating all four levels of verbal aggression, one level of physical aggression against objects and adynamia/lack of initiation, then the client's total level score would be 6 (i.e. 4+1+1).**

**The clinical-weighted severity score was computed by adding together the severity score for each of the levels of behaviour endorsed for the client across the 9 domains (out of a total of 88). For example, if a client was rated as demonstrating all four levels of verbal aggression, sexual talk, non-genital touching and an adynamia/lack of initiation severity rating of 3, then the client's clinical weighted severity score would be 15 (i.e. 1+2+3+4+1+1+3).**

Pearson's correlations of the intra-rating cluster, total levels and clinical-weighted severity scores were 0.68, 0.85 and 0.88 respectively. To evaluate inter-rater reliability two different clinicians rated 26 paediatric clients using the OBS-K. Pearson's correlations of the inter-rating cluster, total levels and clinical-weighted severity scores were 0.79, 0.85 and 0.88 respectively. All correlations were statistically significant ( $p < 0.05$ ). Together these results reveal satisfactory stability and inter-rater reliability of the OBS-K.

In terms of validity, clinician ratings on the OBS-K were correlated with family<sup>8</sup> member ratings on the OBS-K using a convenience sample of 22 clients. Pearson's correlation coefficient size for the cluster, total levels and clinical weighted severity scores were 0.32 ( $p > 0.05$ ), 0.50 ( $p < 0.05$ ) and 0.66 ( $p < 0.05$ ), representing satisfactory correlations between family and clinician OBS-K total levels and clinical-weighted severity scores but not the cluster score.

The validity of the OBS-K was also assessed by having family members complete other validated measures of child behaviour, participation and family impact. Given that only those children who met criteria for challenging behaviour using the OBS-K were included in this pilot analysis it was hypothesised that they would also demonstrate significant problems on these other measures. These other measures included the Child Behaviour Checklist (CBCL; Achenbach & Rescorla, 2001), Behavioural Rating Inventory of Executive Function (BRIEF; Gioia, Isquith, Guy & Kenworthy, 2000), the Child and Adolescent Scale of Participation (CASP; Bedell, 2004) and the Impact on Family Scale (IFS; Stein & Jessop, 1985). The mean score obtained by the children rated is displayed in Table A.1. The mean (and SD) was derived from client T-scores for the CBCL and BRIEF (mean=50; SD=10) whereas it was derived from client raw scores on the CASP and IFS. Not all 22 families completed each of these inventories.

The mean CBCL competence score for the 21 children with TBI and challenging behaviour was considerably lower compared to the normative population. This sample also had a lot more CBCL behavioural problems compared to the normative population. Eighteen out of 21 (86%) scored within the clinically abnormal range in at least one area of competence. Seventeen out of 21 (81%) scored within the clinically abnormal range in at least one behavioural problem area. Table A.1 shows the number (and percentage) of children who scored in the clinically abnormal range in each of the areas of competence or behavioural problems assessed by the CBCL. The high number of competence and behavioural problems in this group of children is not surprising given that they had met criteria for challenging behaviour, providing further support for the validity of the OBS-K.

<sup>8</sup>Families were of clients that were known to have met criteria for challenging behaviour (see Table 1) using clinician rated OBS-K forms.

Except for the “Organisation of Materials” subscale, the mean subscale and index scores for each of the 19 children assessed using the BRIEF was considerably higher than that seen in the normative population. Fourteen of these children (74%) scored in the clinically abnormal range in at least one of the domains of behavioural executive dysfunction assessed by the BRIEF. Table A.1 shows the number (and percentage) of children who scored in the clinically abnormal range in each of the areas of behavioural executive dysfunction assessed by the BRIEF.

The mean score for each of the 22 children assessed using the CASP was equivalent to that obtained by Bedell’s (2004) normative sample of young people with ABI. Bedell’s normative sample (N=60) scored an average of 79 (SD=19) on the CASP, with scores ranging between 0 and 100.

The mean score for each of the 22 children assessed using the IFS was equivalent to that obtained by Stein and Jessop’s (1985) normative sample of children who had undergone ambulatory care treatment. The Stein normative sample (N=209) scored an average of 59 (SD=10) on the IFS, with scores ranging between 24 and 76. As can be seen in Table A.1 sixteen of the 22 children (73%) scored in the clinically abnormal range on the IFS, demonstrating the significant impact children with TBI and challenging behaviour have on family functioning. Unlike for the CBCL and BRIEF, the clinically abnormal range for the IFS was any score that was at least one standard deviation above the normative mean because the normative sample was not representative of the normal population but was a clinical population itself.

**Table A.1:** Children with challenging behaviour and the CBCL, BRIEF, CASP and IFS

	Mean (SD) <sup>†</sup>	Number scoring in clinically significant range <sup>^</sup>	Percent scoring in clinically significant range <sup>^</sup>
<b>CBCL*</b>			
<b>Competence scales</b>			
-Activity	44.33 (8.97)	2	10
-Social	35.19 (11.15)	8	38
-School	29.14 (9.44)	16	76
-Total	32.95 (9.62)	13	62
<b>Problems scales</b>			
-Anxious-Depression	58.68 (9.67)	2	10
-Withdrawal-Depression	61.91 (9.37)	5	24
-Somatic complaints	60.82 (9.58)	4	19
-Social problems	64.68 (9.39)	5	24
-Thought problems	65.09 (9.98)	9	43
-Attention problems	66.05 (10.60)	7	33
-Rule breaking	57.41 (6.87)	2	10
-Aggressive behaviour	61.55 (9.42)	4	19
Internalising behaviour	59.77 (11.48)	8	38
Externalising behaviour	58.23 (11.13)	8	38
Total behaviour problems	54.91 (10.15)	3	14

**Table A.1:** Children with challenging behaviour and the CBCL, BRIEF, CASP and IFS (continued)

	Mean (SD) <sup>†</sup>	Number scoring in clinically significant range <sup>^</sup>	Percent scoring in clinically significant range <sup>^</sup>
<b>BRIEF<sup>#</sup></b>			
-Inhibition	63.58 (12.01)	7	37
-Shift	62.89 (16.02)	5	26
-Emotional control	61.21 (12.67)	5	26
-Initiation	63.68 (9.78)	5	26
-Working memory	71.16 (11.99)	11	58
-Planning/organising	64.32 (8.72)	5	26
-Organisation of materials	55.74 (8.01)	0	0
-Monitor	65.05 (9.81)	7	37
Behavioural regulation Index	64.47 (12.59)	6	32
Metacognition Index	65.37 (8.75)	8	42
General Executive Composite	66.16 (8.76)	6	32
<b>CASP<sup>§</sup></b>			
-Total participation	75.81 (17.37)	a	a
<b>IFS<sup>§</sup></b>			
-Total impact on family	63.84 (12.13)	16 <sup>b</sup>	73 <sup>b</sup>

\*n=21 #n=19 §n=22

<sup>a</sup>Normative sample scores were not normally distributed so number and percent falling at clinically abnormal range not determined.

<sup>b</sup>For the IFS the clinically significant range was any score one standard deviation above the normative mean.

<sup>†</sup>The mean (SD) was derived from client T-scores on the CBCL and BRIEF whereas it was derived from client raw scores on the CASP and IFS.

<sup>^</sup>The clinically significant range was any score that fell two standard deviations above or below the normative mean for each instrument, reflecting impairment.

In summary, the OBS-K had satisfactory inter - and intra - rater reliability. Clinician ratings also correlated reasonably well with family ratings when comparing two out of the three summary indices. As would have been expected the children with TBI who met criteria for challenging behaviour (on the basis of the OBS-K) also had significant problems in terms of reduced competence, internalising and externalising behavioural problems, executive dysfunction and strained family functioning. These findings provide further support for the validity of the OBS-K.

# APPENDIX B

## OVERT BEHAVIOUR SCALE- KIDS (OBS-KIDS)

### Challenging behaviours

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

### What is this scale for?

This scale is being designed to clarify the types of observable challenging behaviours that children and young people with an Acquired Brain Injury (ABI) may demonstrate. 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 child or young person (including family members and service providers). The OBS-Kids is being developed for use with children and young people aged pre-school to 18 years.

### What does this scale measure?

There are 9 categories 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
- Lack of initiation

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

### How to use this scale

For each of the 9 categories of behaviour there is a heading (e.g., verbal aggression) and a relevant subscale. If the child or young person exhibits no sign of that category of behaviour, mark the “no” box and go to the next behaviour.

If the child or young person 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. At the end of the scale there is a section entitled “OTHER”. Please record any behaviours that you have observed the child or young person engaging in that do not fit into any of the preceding categories. Please ensure you complete this section last as most of the behaviours observed will likely fit into one of the 9 categories provided.

- If a behaviour appears to fit 2 categories, use the single most appropriate one.
- Tantrums are a common behaviour in young children. There is no specific category for tantrums. Please record the observable behaviour (e.g. screaming; kicking the floor) in the appropriate category provided (e.g. verbal aggression; physical aggression)

### Timeframe

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

### More information

This scale has been modified by Melbourne Citymission in conjunction with the ABI Behaviour Consultancy from the OBS developed by The ABI Behaviour Consultancy. Kelly, Todd, Simpson, Kremer, & Martin (2006). The Overt Behaviour Scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury* 20 (31) pp 307 – 319.

Date of completing OBS-K	
Age of Child	
Rater's name	
Child's name / identifier	
Informant's name	
Informant's role (e.g. parent)	

## HOW TO RATE BEHAVIOURS

### Tick each level that is a problem

For each category 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 (✓) 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 needing additional staff, altered procedures, dealing with complaints from families or other residents, being suspended or expelled from school or having to acquire additional supports such as psychiatrists, police, or behaviour intervention. 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	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any verbal aggression?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)</p> <p>YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	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. May include comments about a person's race or sexual orientation (e.g., "You are stupid!", "idiot"; "You're a fag!").	2			
Swearing, use of foul language, moderate threats clearly directed at others or self (e.g., "F___ off you bastard!"; a young child saying threatening lines from films or TV shows).	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	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any physical aggression?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)  YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
<b>Physical aggression against objects</b>				
Slams doors, scatters clothing, makes a mess in clear response to some antecedent (trigger).	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 <i>Physical aggression against other people</i>	4			
<b>Physical act against self</b>				
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			
<b>Physical aggression against other people</b>				
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	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any inappropriate sexual behaviour?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
<b>Physical aggression against objects</b>				
<p><b>Sexual talk</b></p> <ul style="list-style-type: none"> <li>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.</li> <li>Explicit accounts of sexual activities (e.g., "When I am with a woman I like to ...", "you want to kiss her ...").</li> </ul>	1			
<p><b>Touching (non genital)</b></p> <ul style="list-style-type: none"> <li>Touching other people who do not want to be touched (but contact does not involve genitals). For example kissing hand, arm or cheek, putting arm around shoulder, patting someone's knee, rubbing or caressing arm or leg or back.</li> <li>Also includes touching clothing (e.g., lifting skirts)</li> </ul>	1			
<p><b>Exhibitionism</b></p> <ul style="list-style-type: none"> <li>"Flashing", exhibiting genitals, undressing in public.</li> <li>Failing to dress (e.g., walking about house without clothes on when coresidents could be or are present. Answering door when naked).</li> </ul>	2			
<p><b>Masturbation</b></p> <ul style="list-style-type: none"> <li>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).</li> </ul>	2			
<p><b>Touching (genital)</b></p> <ul style="list-style-type: none"> <li>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).</li> </ul>	3			
<p><b>Coercive sexual behaviour, Rape</b></p> <ul style="list-style-type: none"> <li>Attempt to forcibly undress another person.</li> <li>Use of threat to obtain sex.</li> <li>Sexual penetration of another person who has not consented</li> </ul>	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.)

PERSEVERATION / REPETITIVE BEHAVIOUR	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any perseveration/repetitive behaviour?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	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: "What time is it?", "Can we go to Mc Donalds?"; talking about the same topic over and over)	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)	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	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any wandering/absconding?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	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, school staff areas, kitchen)	1			
Leaving the familiar, 'safe', environment when there is a good risk of becoming lost or seriously harmed (e.g, leaving school grounds to return to family home, running across road, running away parent at the supermarket/shopping centre, 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/parent/teacher who attempt to stop or restrain them).	3			



INAPPROPRIATE SOCIAL BEHAVIOUR	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any inappropriate social behaviour?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
<p><b>Socially awkward</b></p> <ul style="list-style-type: none"> <li>▪ Inappropriate laughter.</li> <li>▪ Failure to monitor personal hygiene (e.g., does not shower regularly).</li> <li>▪ Excessive apologising or thanking</li> <li>▪ Standing too close to others</li> <li>▪ Overly affectionate and friendly to others</li> <li>▪ Failure to pick up on nonverbal cues (that others are bored, the joke was not funny, the conversation is over)</li> <li>▪ Inappropriate comments; saying things in a tactless way</li> </ul>	1			
<p><b>Nuisance / annoyance</b></p> <ul style="list-style-type: none"> <li>▪ Interrupts other people's conversations</li> <li>▪ Actively does things to seek attention (e.g., spills food, rings buzzer, "Teacher can you help me?")</li> <li>▪ Inconsiderate of other people (e.g., hogging TV channel or remote control)</li> <li>▪ Nagging, impatient (e.g., always wanting something else to be done; can not tolerate waiting for supermarket queues)</li> <li>▪ "Butts in" to other people's affairs. (e.g., advising staff/management on how to improve residence, reporting on other clients' activities.)</li> <li>▪ Tells other people to do something- gets others to do their 'dirty work'(e.g. "go hit that boy over there")</li> </ul>	2			
<p><b>Noncompliant / oppositional</b></p> <ul style="list-style-type: none"> <li>▪ Responds "no!" to prompts to do things. E.g. saying no or removing clothes when parent/carer tries to dress them</li> <li>▪ Refuses to discuss problem behaviours with staff. Refuses to attend school. Refuses to attend appointments (e.g. Juvenile justice, drug and alcohol)</li> <li>▪ Will not follow toilet or shower routines. Refuses to take medication.</li> <li>▪ Rejects or dismisses service providers who are helpful with home care.</li> <li>▪ Intentional lying that is not due to poor memory (e.g., denying drug use or stealing; fabricating stories to cover tracks)</li> <li>▪ Will not (as opposed to Can not) follow rules. (e.g., leaving without telling someone where s/he is going)</li> </ul>	3			

INAPPROPRIATE SOCIAL BEHAVIOUR	Severity	Levels	Frequency (rate 1 ... 5)	Impact (rate 1 ... 5)
<p><b>Has the child or young person shown any inappropriate social behaviour?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>		Tick each level that is a problem (✓)	1 = < 1/month 2 = 1/month or more 3 = 1/week or more 4 = 1/day 5 = multiple daily	1 = no impact 2 = minor 3 = moderate 4 = severe 5 = extreme
<p><b>Petty crime or Unlawful behaviour</b></p> <ul style="list-style-type: none"> <li>▪ Driving while unlicensed</li> <li>▪ Underage drinking</li> <li>▪ Fraud (e.g., writing dishonoured cheques)</li> <li>▪ Obtains goods by theft or deceit</li> <li>▪ Stealing (e.g., steals cigarettes from other residents, steals clothes or food from shops; materials from building sites)</li> </ul>	4			
<p><b>Presents a danger/risk to self or others</b></p> <ul style="list-style-type: none"> <li>▪ Overly familiar/friendly to strangers e.g. gets into cars with strangers; goes home with strangers</li> <li>▪ Lights fires dangerously. (e.g., smoking in bed, starting bonfire near gas cylinder)</li> <li>▪ Wheeling wheelchair in middle of road.</li> <li>▪ Climbs ladders, benches, high objects that are unsafe</li> <li>▪ Excessive use of alcohol, cigarettes, or other substances where that is the key behaviour leading to risk or actual harm to self or others.</li> <li>▪ Uses provision of sex to gain access to goods (such as money, cigarettes, drinks) or services.</li> </ul>	4			
<p><b>Faecal Smearing</b></p> <ul style="list-style-type: none"> <li>▪ Child smears faeces. This could be related to different reasons including sensory or control</li> </ul>	4			

LACK OF INITIATION	Severity <i>i.e., Amount of prompting required (rate 1 ... 5)</i>	Impact <i>(rate 1 ... 5)</i>
<p><b>Has the child or young person shown lack of initiation?</b></p> <p>NO <input type="checkbox"/> (go to next behaviour)            YES <input type="checkbox"/> (rate the subscale below)</p>	<p>1 = less than once/day            2 = approx. once/day            3 = more than twice/day            4 = many times/day            5 = all tasks, everyday</p>	<p>1 = no impact            2 = minor            3 = moderate            4 = severe            5 = extreme</p>
<p><b>EXAMPLES</b></p> <ul style="list-style-type: none"> <li>▪ The person 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.</li> <li>▪ However, the person may engage in activities if someone else prompts them. Once asked to "Wash the dishes", the person may then commence and complete the task. A student may need to be prompted to leave the classroom at the change of class or to stop one exercise and begin another.</li> <li>▪ 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"?</li> <li>▪ 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".</li> </ul>		

**Other**

Please record any other behaviour that you have observed that does not fit into any of the preceding categories.  
 Please provide a full description of the observable behaviour:

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## CLIENT FORM (To be completed by clinician for each client included in study)

### 1. Residential Location of Client?

- Urban       Regional       Remote
- 

### 2. What services do you provide to this client (can have more than one)?

- |   |  |
|---|--|
| <input type="checkbox"/> Assessment   | <input type="checkbox"/> Behaviour therapy                           |
| <input type="checkbox"/> Individual psychotherapy / counselling                   | <input type="checkbox"/> Therapy (ADLs, iADLs, motor, communication) |
| <input type="checkbox"/> Psycho-education   | <input type="checkbox"/> Behavioural support                         |
| <input type="checkbox"/> Crisis intervention                                      | <input type="checkbox"/> Education liaison                           |
| <input type="checkbox"/> Case Management (liaison, support, monitoring, advocacy) | <input type="checkbox"/> Cognitive therapy                           |
| <input type="checkbox"/> Carer / family education and training                    |  |
- 

### 3. BIRP Staff Involved in Care (can have more than one)?

- |   |   |
|---|---|
| <input type="checkbox"/> Social Work              | <input type="checkbox"/> Clinical Psychology  |
| <input type="checkbox"/> Neuropsychology          | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Physio-Therapy           | <input type="checkbox"/> Play Therapy         |
| <input type="checkbox"/> Neurology                | <input type="checkbox"/> Psychiatry           |
| <input type="checkbox"/> Rehabilitation Physician | <input type="checkbox"/> Speech Pathology     |
| <input type="checkbox"/> Case Manager             |   |
- 

### 4. Current Additional Management Services (can have more than one)?

- |  |   |
|--|---|
| <input type="checkbox"/> GP / specialist                         | <input type="checkbox"/> Education Assistance Including Teacher Aide, Tutor |
| <input type="checkbox"/> Community Health Service                | <input type="checkbox"/> Mental Health Service / Psychotherapy              |
| <input type="checkbox"/> Respite                                 | <input type="checkbox"/> Legal Services                                     |
| <input type="checkbox"/> Family psycho-education                 | <input type="checkbox"/> Counselling  |
| <input type="checkbox"/> Drug and Alcohol Service                | <input type="checkbox"/> Family / Friend                                    |
| <input type="checkbox"/> Behavioural Management                  | <input type="checkbox"/> Living Skills Training                             |
| <input type="checkbox"/> Community Agency / Home Support Service | <input type="checkbox"/> None   |
| <input type="checkbox"/> Disability Services                     |   |
- 

### 5. What Management Services do you think the client would benefit from but are not yet provided for the client and/or family (can have more than one)?

- |  |   |
|--|---|
| <input type="checkbox"/> GP / specialist                         | <input type="checkbox"/> Education Assistance Including Teacher Aide, Tutor |
| <input type="checkbox"/> Community Health Service                | <input type="checkbox"/> Respite  |
| <input type="checkbox"/> Mental Health Service / Psychotherapy   | <input type="checkbox"/> Vocational Assistance                              |
| <input type="checkbox"/> Family psycho-education                 | <input type="checkbox"/> Legal Services                                     |
| <input type="checkbox"/> Drug and Alcohol Service                | <input type="checkbox"/> Counselling  |
| <input type="checkbox"/> Behavioural Management                  | <input type="checkbox"/> Family / Friend                                    |
| <input type="checkbox"/> Community Agency / Home Support Service | <input type="checkbox"/> Living Skills Training                             |
| <input type="checkbox"/> Disability Services                     | <input type="checkbox"/> None   |

6. Over the past 3 months have there been any concerns or issues with any of the following for the client and/or family (tick to indicate; can have more than one)?

- |   |  |
|---|--|
| <input type="checkbox"/> Family breakdown | <input type="checkbox"/> Employment                |
| <input type="checkbox"/> Accommodation    | <input type="checkbox"/> Legal                     |
| <input type="checkbox"/> Health           | <input type="checkbox"/> Loss of Program / Service |
| <input type="checkbox"/> Education        | <input type="checkbox"/> None                      |

7. Is there a pre-injury history of learning disability?

- No  Yes

8. Is there a pre-injury history of developmental disability?

- No  Yes

9. Is there a pre-injury history of clinically significant psychiatric disturbance?

- No  Yes

10. Please indicate the number that best describes how much stress you have experienced in working with this client:

0 ■	1 ■	2 ■	3 ■	4 ■	5 ■	6 ■
No Stress			Moderate Stress			Severe Stress

11. Please indicate the number that best describes how complex you have found it to work with this client:

0 ■	1 ■	2 ■	3 ■	4 ■
No Complexity	Minor Complexity	Moderate Complexity	Substantial Complexity	Extreme Complexity
Routine management	Some challenges, easily managed	Some challenges, most easily managed	Multiple challenges, many difficult to manage	Multiple challenges, most / all difficult to manage

12. How confident are you in the accuracy of your answers? (select one)

Not at all confident ■	Somewhat confident ■	Mostly confident ■	Very confident ■
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# APPENDIX C

## QUESTIONS USED TO GUIDE SEMI-STRUCTURED INTERVIEW WITH CLINICIANS ABOUT PAEDAITIC CHALLENGING BEHAVIOUR CLIENTS INCLUDED IN QUALITATIVE REVIEW:

1. What were the main issues at the time of referral to the community team?
2. What were the goals that the team were working on with the person?
3. What were the types of challenging behaviours that 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 premorbid 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 D

## CLIENT DEMOGRAPHIC CHARACTERISTICS

A summary of the demographic characteristics of all paediatric clients included in the study is displayed in Table D.1. The mean age of children was 13.7 (SD=2.8).

**Table D.1:** Demographic characteristics of paediatric clients

Demographic variables	n	%
<b>Gender</b>		
Female	64	35.2
Male	118	64.8
<b>Place of birth</b>		
Australia	139	76.4
Outside Australia	12	6.6
Unknown	31	17.0
<b>Indigenous status</b>		
Non-indigenous	133	73.1
Indigenous	9	4.9
Unknown	40	22.0
<b>Geographic location</b>		
Urban	138	75.8
Regional	33	18.1
Remote	4	2.2
Unknown	7	3.8

## CLIENT INJURY CHARACTERISTICS

The clinical injury characteristics of all these clients included in the study is displayed in Table D.2. The data shows that:

- 42% of children sustained their injury in the first five years of life
- The sample was skewed toward the severe end of the TBI spectrum
- Motor vehicle accidents accounted for 60.9% of injuries

**Table D.2:** Injury related characteristics of paediatric clients

Injury variables	n	%
<b>Age at injury</b>		
less than 1 year	20	11.0
1 to 2 years	28	15.4
3 to 5 years	29	15.9
6 to 12 years	71	39.0
13 to 18 years	34	18.7
<b>PTA ranges<sup>§</sup></b>		
less than 24 hours	10	11.0
2-6 days	12	13.2
1-4 weeks	37	40.6
1-6 months	18	19.8
Unknown	14	15.4
<b>Injury circumstance</b>		
MVA passenger	21	11.5
MVA pedestrian	22	12.1
MVA bicycle	1	0.5
MVA unspecified	66	36.3
MBA	1	0.5
Assault/Non-accidental injury	20	11.0
Fall	24	13.2
Sport/leisure	19	10.4
Other traumatic brain injury	7	3.8
TBI but circumstance unknown	1	0.5

<sup>§</sup>PTA can only be assessed for children aged 7 years and older (n=91).



## ADDITIONAL CLINICAL CHARACTERISTICS ABOUT CLIENTS

The clinical informants in the study completed a form containing questions about presence of premorbid learning disability, developmental delay and psychiatric disturbance. In addition, clinical informants provided information about the level of psychosocial functioning of paediatric clients in the three months before survey. These characteristics are detailed below.

### Premorbid learning, developmental and psychiatric history

Clinical informants rated the prevalence of premorbid conditions, finding that:

- 33 (18.1%) clients had a learning disability
- 6 (3.3%) clients had a developmental delay
- 12 (6.6%) clients had a significant clinical history of psychiatric disturbance

### Psychosocial breakdown over the preceding three months

Clinical informants rated whether or not paediatric clients experienced significant problems in seven psychosocial domains over the preceding three months (see Table D.3). As can be seen paediatric clients were more likely to experience breakdown in their educational situation compared to any other aspect of their life.

**Table D.3:** Psychosocial breakdown of clients

	n	%
Family breakdown	18	9.9
Accommodation	11	6.0
Health	22	12.1
Education	53	29.1
Employment	6	3.3
Legal	16	8.8
Loss of program/service	4	2.2
No breakdown	93	51.1

## SERVICE-RELATED CHARACTERISTICS OF CLIENTS

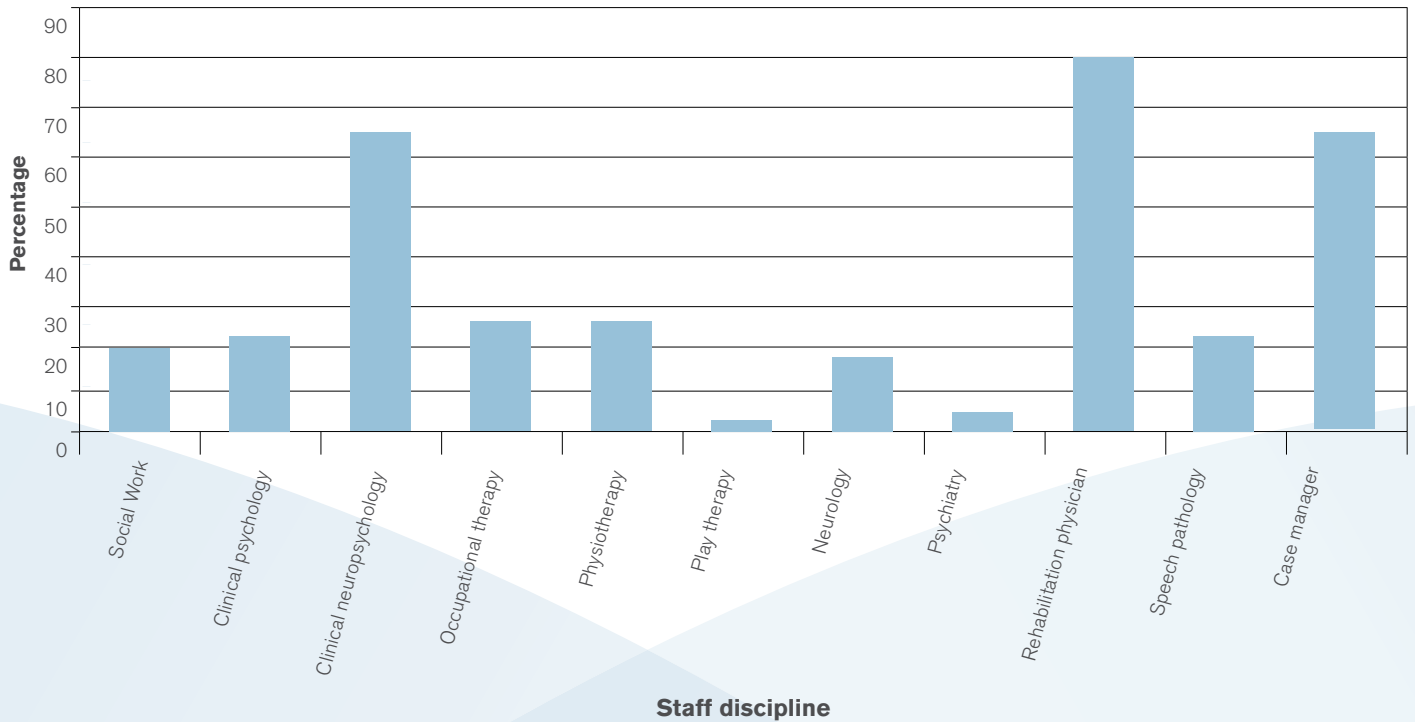
The clinical informants provided information about the services each paediatric client received from BIRP and non-BIRP service providers.

### BIRP SERVICES

#### BIRP staff providing services to clients

Data were collected on the number of BIRP staff involved with paediatric clients across the three units. Staff most commonly involved with clients were rehabilitation physicians, clinical neuropsychologists and case managers (79.7%, 64.8% and 64.3% respectively) followed by occupational therapists. The median number of staff involved with clients was 3.0 (range=0-10). See Figure D.1.

Figure D.1: BIRP staff involved with clients



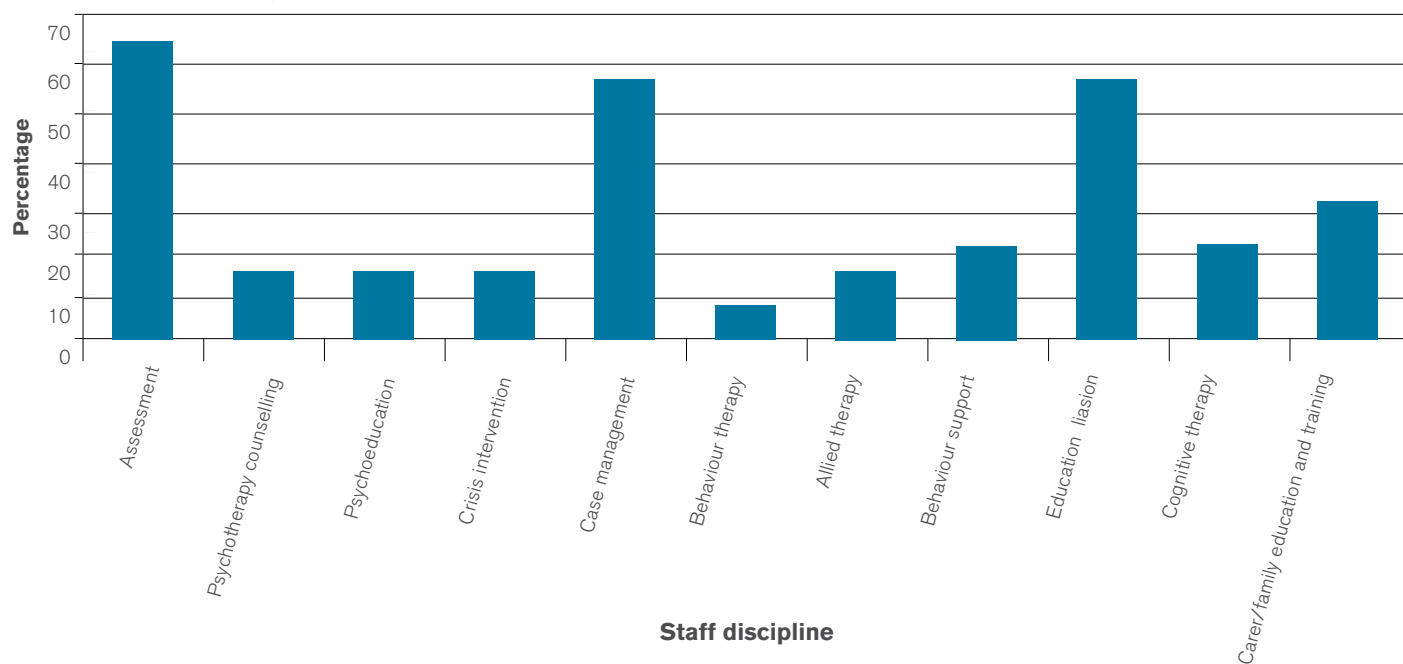
#### Services provided by BIRP

The most common service provided by BIRP units to clients was case assessment, received by two-thirds of clients, followed by case management and education liaison, received by over half of clients. The median number of services provided by the paediatric BIRP units to clients was 3 (range=0-8). See Figure D.2.

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

BIRP Clinical informants rated the degree of stress they experienced in working with their clients and how complex they viewed their clients (see Table D.4). As can be seen stress levels were positively skewed. Both stress and complexity were strongly correlated (spearman-rank  $r=0.75$ ,  $p<0.05$ ).

**Figure D.2:** Services provided by BIRP to clients



**Table D.4:** Ratings of stress and complexity when working with clients

	n	%
<b>Stress</b>		
-0 no stress	38	20.9
-1	47	25.8
-2	43	23.6
-3 moderate stress	30	16.5
-4	16	8.8
-5	5	2.7
-6 severe stress	3	1.6
<b>Complexity</b>		
-0 no complexity	21	11.5
-1 minor complexity	55	30.2
-2 moderate complexity	58	31.9
-3 substantial complexity	38	20.9
-4 extreme complexity	10	5.5

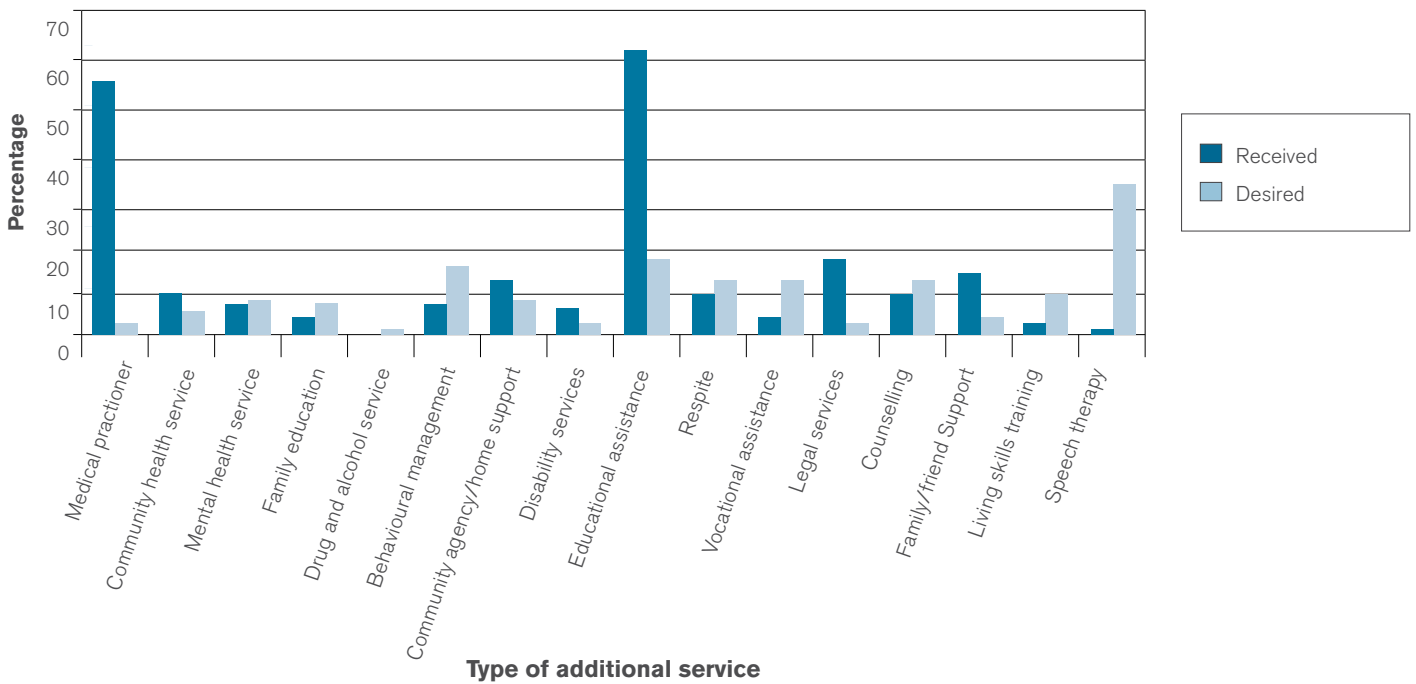
### ADDITIONAL (NON-BIRP) SERVICES

The proportion of paediatric clients receiving additional services outside of the three paediatric BIRP units was also documented (Figure D.3). A diverse range of services were documented. The most common type of non-BIRP services accessed by clients was educational assistance, followed by services provided by medical practitioners. The median number of additional services received by clients was 2.0 (range=0-11).

As a measure of unmet need, clinicians also identified additional services that were required but had not been accessed or received by the client. As can be seen in Figure D.3 the most common desired service was speech therapy for 33% of clients. The median number of additional services desired for clients was one (range=0-7).

For nine of the 16 service types, the unmet need (clients for whom the service was desired) was greater than the number of clients accessing such services. These areas of unmet need included: mental health service, family education, drug and alcohol service, behavioural management, respite, vocational assistance, counselling, living skills training and speech therapy.

**Figure D.3:** Non-BIRP services accessed/received by clients or desired for them



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