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 162 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%); sleep disturbance/loss 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 levels 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.

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.

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.
**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.

Recommendation 20:
BIRP 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 (e.g. 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.

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.

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.