

# 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:

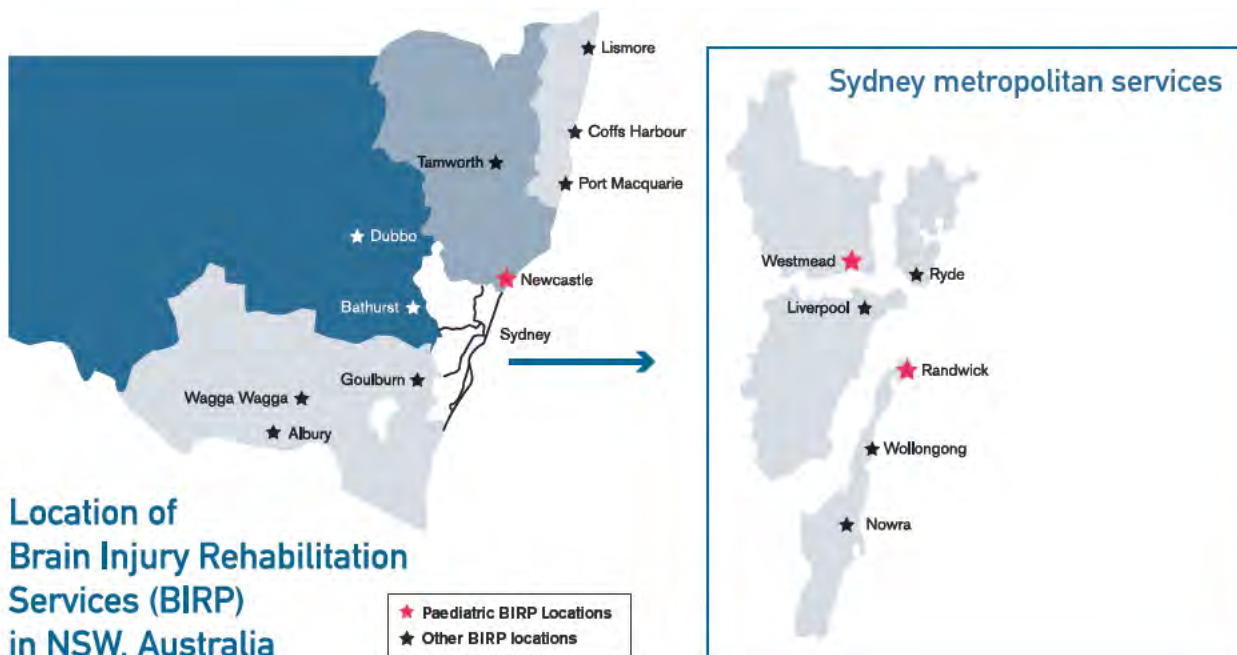
- Challenging behaviour was identified by the Brain Injury Rehabilitation Program (BIRP) as one of the top state-wide priorities requiring urgent attention
- To create an evidence base for coordinated state-wide management of challenging behaviours among people with TBI that will have flow-on effects 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