INTRODUCTION

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

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

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

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

The CBP was important for the following reasons:

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

Context of current study

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

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