

# Continence and brain injury:

Improving independence  
and quality of life, and  
reducing cost of care

**Brightwater Care Group**

**Brightwater Research Centre**

Brightwater House, Level 3  
355 Scarborough Beach Road  
Osborne Park WA 6017

**W** [brightwatergroup.com](http://brightwatergroup.com)

**E** [research.enquiries@brightwatergroup.com](mailto:research.enquiries@brightwatergroup.com)

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The Insurance Commission is the WA Government State insurer providing injury insurance to motorists and self-insurance to the Government. Its community engagement program aims to prevent or minimise the risk of injuries insured by the Insurance Commission and improve the rehabilitation and care outcomes for its clients.

Attendant care costs are significant for the Insurance Commission, particularly for those clients who are catastrophically injured in vehicle crashes. This research into assistive toileting technologies aims to increase client independence, improve quality of life, and decrease care costs.

**For more information on the Insurance Commission, please visit: [www.icwa.wa.gov.au](http://www.icwa.wa.gov.au)**

**Report Authors:** *Hayley Jackson, Angelita Martini, Katie Beros, and Annelize Prinsloo, Brightwater Research Centre, Brightwater Care Group.*

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# Abstract

**Purpose:** Problems with continence are common in people with an acquired brain injury (ABI). This project aimed to investigate, review, and trial assistive devices to support people with an ABI to toilet more independently, improve quality of life, and reduce the cost of care.

**Methodology:** This mixed-methods project used a sample of 16 clients with ABI and continence/toileting issues receiving community-based rehabilitation for brain injury at two Brightwater rehabilitation sites. Data collected on client outcomes included: estimated care hours, cost of care, cost of consumable products (e.g., continence pads), independence in daily living activities, and quality of life. These data were collected at the start of the study (Time 0) and three months after assistive devices were implemented (Time 3). Practices in continence care were examined using qualitative observation and surveys of 24 staff directly involved in clinical care at participating rehabilitation sites.

**Results:** Between Time 0 and Time 3, weekly care hours required for toileting/continence declined by an estimated 4.3 hours per client, which translated to an estimated weekly cost reduction of \$633.29 per client. The average daily cost of consumable items reduced by \$9.91 per client after intervention. Significant improvements in client independence were also found, with observed improvements in total as well as cognitive and motor independence. Despite these improvements, client-reported quality of life declined over the study period; however, this was not statistically significant. Qualitative observations showed limitations of current practices in continence management. Staff surveys revealed gaps in staff knowledge and practice around continence care and the need for improved interdisciplinary communication.

**Conclusions:** Managing continence-related problems in the ABI population with assistive devices is effective at reducing the need for staff intervention and cost, as well as improving functional independence, wellbeing and dignity. Consistent with previous research, current practice in continence management can be improved to provide client-centred and evidence-based care using a multidisciplinary team approach. The findings have wide-ranging policy implications and should be taken into consideration when planning treatment and rehabilitation services, and in the preparation and funding of care plans.

# Executive Summary

## Background

**Incontinence greatly increases the cost of care for people with an acquired brain injury (ABI).**

Many people with an ABI are dependent on staff intervention—in some cases, from more than one staff member—to assist with toileting.

Toileting for people who are reliant on others for assistance not only reduces their independence but also profoundly impacts health-related quality of life. Currently, there are few effective and cost-efficient strategies to underpin continence management after ABI.

This report documents a research project that aimed to decrease the cost of care, increase independence, and improve quality of life for clients with an ABI receiving staged, community-based injury rehabilitation from Brightwater Care Group (WA). The project trialled assistive toileting devices for 16 people with an ABI and continence difficulties receiving brain injury rehabilitation at two Brightwater sites. Current sector practices in continence management are also documented.

## Key Findings

**The key project findings identified that intervention with a comprehensive assessment, individually tailored management plans, and assistive devices:**

- Reduced toileting care hours by **4.3 hours per client per week**, which represented a reduction in average weekly care costs of **\$633.29 per client**.
- Reduced the average daily cost of consumable products for continence (e.g., continence pads) by **\$9.91 per client per day**.
- **Improved client independence in activities of daily living**, with statistically significant improvements in total as well as cognitive and motor subscales of the FIM+FAM three months after implementation (Time 3).

Despite these improvements, client-reported quality of life decreased over the study period, but these changes were not statistically significant.

**Seven key limitations to existing practice in continence were identified:**

1. Insufficient emphasis on client-centred continence care.
2. Poor coordination of care.
3. Lack of standardised assessment protocols and procedure.
4. Limitations of clinical documentation.
5. Uncertainty about funding for continence products.
6. Need for further staff education and training.
7. Lack of staff collaboration.

## Conclusions

Intervention with a comprehensive continence assessment, tailored management, and assistive devices in the ABI population can reduce care hours and thus cost. Intervention can also improve functional independence, both in cognitive and physical domains. However, intervention did not positively impact client-reported quality of life.

Previous research in the sector demonstrated that continence management practices are sub-optimal. The findings of this report are consistent with these earlier findings, and continence practice can be improved to provide client-centred, evidence-based care using a whole team approach.

These findings have wide-ranging policy and practice implications and should be taken into consideration when planning treatment and rehabilitation services, and in the preparation and funding of care plans.

## Recommendations

**Moving forward, it is recommended the Insurance Commission, as the research funder:**

1. Engage with service providers to its clients with catastrophic injury and probable, uncertain, or complex incontinence, to ensure a comprehensive continence assessment is completed by a qualified continence specialist.
2. Consider how best to ensure future clients with catastrophic injury undergo early and regular comprehensive continence assessment.
3. Support industry-wide seminars/workshops on continence to improve sector-wide practice.

**Sector-wide recommendations include:**

1. Adopt a client-centred approach.
2. Review current policies and procedures against clinical practice guidelines.
3. Ensure standardised clinical documentation to enable the effective exchange of information between staff and to ensure continuity of care.
4. Improve continence management role clarity and understanding of roles.
5. Promote a multidisciplinary approach.
6. Increase staff education and training.
7. Support a multidisciplinary approach.
8. Staff education and training.

**Recommendations for future research include:**

1. Use larger samples of clients with ABI for replicability, generalisability, statistical significance, and effect sizes of findings from this study.
2. Replicate the study in an in-home setting and over longer time periods.
3. Examine the possible causes of the decline in HRQOL.
4. Examine the lived experiences of persons with ABI and incontinence to foster a client-centred approach.



# 1

## Introduction

More than 700,000 Australians are estimated to have an acquired brain injury (ABI) [1]. This group of disorders includes all types of brain injury occurring after birth, including brain injury caused by traumatic events (i.e., traumatic brain injury), such as motor vehicle crashes, as well as non-traumatic events, such as stroke and hypoxia. ABI can cause long-term disability and disrupt quality of life due to impairment in cognitive, physical, emotional, and independent functioning [2]. ABI is also associated with a considerable burden on the healthcare budget.

Within the ABI population, incontinence is common. For example, as many as 85.9% of people with ABI from traumatic causes complain of urinary symptoms, and up to 68% report faecal incontinence [3, 4]. Urinary incontinence is also reported to occur in 32%–79% of people with ABI from stroke in the first month after stroke [5–11] and remains prevalent compared to population controls up to 10 years later [12]. At least 23%–30% of stroke survivors also experience faecal incontinence [13, 14]. Little has been published on the prevalence of incontinence following brain injury from other causes, such as hypoxia.

The International Continence Society (ICS) defines urinary incontinence as “the complaint of any involuntary leakage of urine” [15], and faecal incontinence has been defined as “any involuntary loss of faecal material” [16]. Many people with ABI are dependent on staff intervention—in some cases, from more than one staff member—to assist with toileting. This greatly increases the cost of care for people with an ABI and has implications for a person’s quality of life and independence in activities of daily living. Therefore, effective, cost-efficient, and feasible ways of managing continence-related problems in this population are urgently needed.

This project aimed to decrease the cost of care, increase independence, and improve quality of life for clients with ABI receiving staged, community-based injury rehabilitation at Brightwater.

The project had four primary objectives:

1. Investigate, review, and trial technology to support people to toilet more independently.
2. Identify opportunities for change in practice (i.e., increase independence, decrease staff intervention).
3. Determine the change in quality of life for residents using assistive toileting technologies.
4. Provide a final report and recommendations to the Insurance Commission of Western Australia (Insurance Commission) and Brightwater.

## Structure of this Report

The report is arranged as follows:

- **Chapter 2** provides a review of the published literature on the economic cost of incontinence and its impact on quality of life and functional outcomes in people with an ABI. A review of current clinical practices in continence management is also provided, along with a review of the literature on the impact of different continence management methods on quality of life.
- **Chapter 3** reports on the goals of the research project.
- **Chapter 4** describes the project methodology, including research participants, setting, and design, as well as giving details of the intervention, outcome measures, and data analytic approach.
- **Chapter 5** reports on the results of the intervention, including change in client outcomes after intervention overall and separately by brain injury diagnosis (stroke, trauma, hypoxia) and level of dependency at baseline (low, medium, high). The outcomes described are required care hours and cost of care, cost of consumable products, independence, and quality of life. Demographic and clinical data of participating clients is reported in this chapter, as well as client reports of satisfaction with the trialled devices.
- **Chapter 6** gives the results of qualitative observation and staff surveys regarding current practice in continence management. Seven key findings are discussed: (1) insufficient emphasis on client-centred care, (2) poor coordination of care, (3) lack of standardised assessment protocols and procedure, (4) limitations of clinical documentation, (5) uncertainty about funding for continence products, (6) need for further staff education and training, and (7) lack of staff collaboration.
- **Chapter 7** summarises the key findings of the report, including both the outcomes of the project intervention and current practice in continence. The discussion in this chapter situates the findings in the context of previous research in the sector and proposes their implications for practice.
- **Chapter 8** provides broad conclusions derived from the project and makes recommendations for the sector, the Insurance Commission, and future research work.

# 2

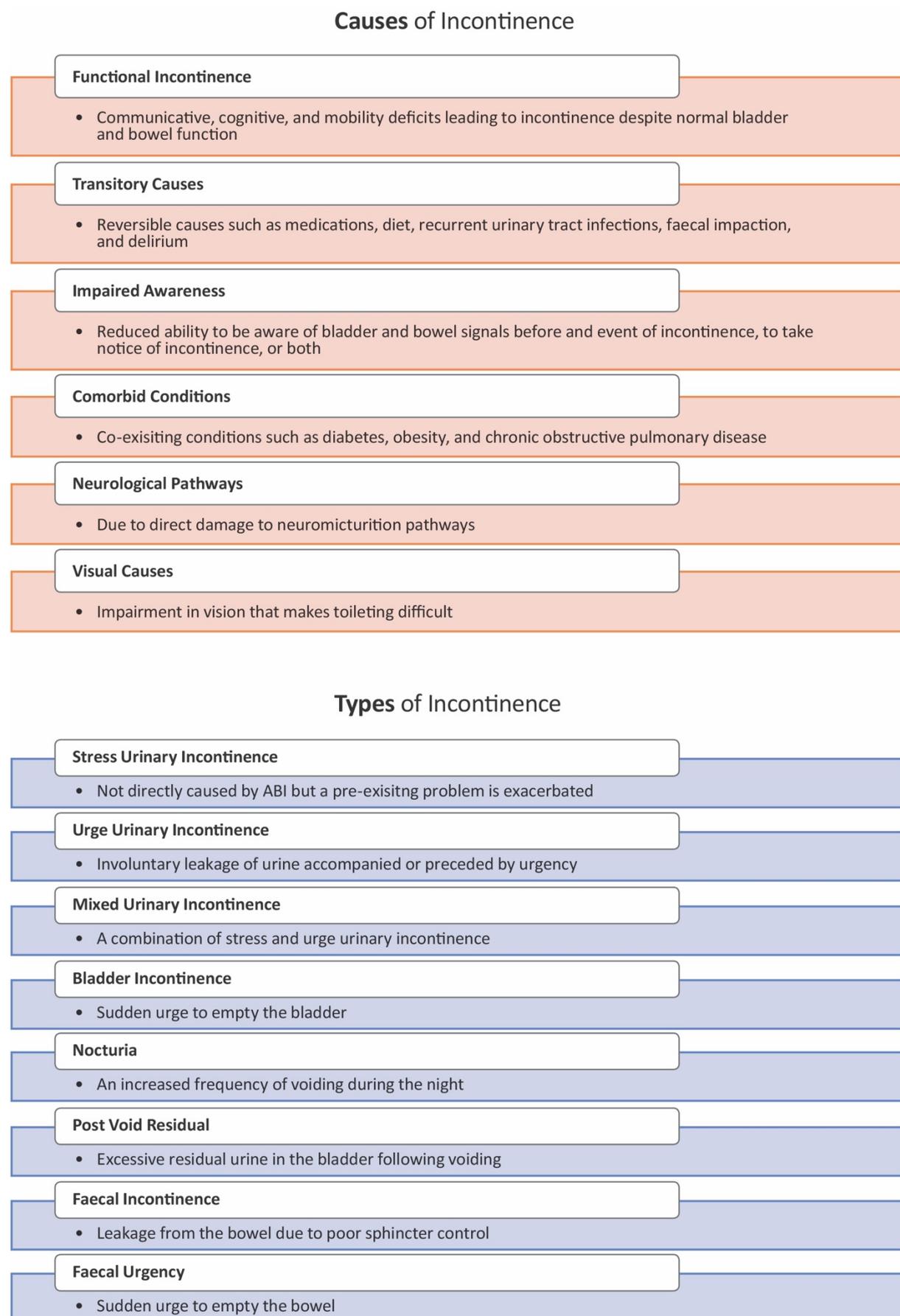
## Literature Review

### 2.1 The Causes of Incontinence Following Brain Injury

There are many reasons why a person may not have voluntary control over their bladder and bowel following brain injury. In addition to problems relating to the storage and elimination of urine and faeces, people with ABI may also have impairments in mobility, dexterity, cognition and communication, which can prevent them from achieving the desired control of bladder and bowel [17, 18]. Figure 1 summarises the different causes and types of incontinence following ABI.

The care of clients with continence problems can require multi-staff interventions to assist with toileting, including transfers to the toilet, removing clothing, assisting with balance, sitting on the toilet, maintaining hygiene, and dressing. Additionally, staff may be involved in managing diet and fluid intake, carrying out behavioural interventions (e.g., prompted or scheduled voiding, bladder training, habit retraining, pelvic floor muscle training), prescribing and administering medications (e.g., anticholinergics, adrenergics), catheterisation, and removing environmental barriers (e.g., effective management of ward furniture and equipment) [19, 20]. Continence problems can also lead to extra laundry expenses and additional items.

Figure 1. The Causes and Types of Incontinence following ABI



*The Insurance Commission of Western Australia estimates that it spends approximately \$4 million per year across its WA motor injury insurance schemes for carers assisting people with car-crash injuries to go to the toilet.*

*The Insurance Commission reported that the average cost of care for toileting its clients is \$57 an hour, as an average rate for day/night/weekend care.*

## 2.2 The Economic Cost of Incontinence

Incontinence in Australia is associated with a significant economic cost. In 2010, the estimated total health system expenditure on incontinence was \$270.8 million, with the majority (74%) contributed by State and Federal Governments [21]. Additionally, the projected cost of community care and expenditure on continence aids and equipment (e.g., pads, laundry, bed protectors) was approximately \$248 million. When estimates of the burden of incontinence, productivity losses, and the cost of informal carers are included in these projections, the estimated annual economic cost of incontinence in Australia is about \$66.7 billion [21].

Incontinence greatly increases the cost of care. Currently, however, there are no published Australian data on these costs in the ABI population. Consequently, the costs associated with continence-related problems in this vulnerable population are not well understood. Estimates from research studies using other groups (e.g., gender, age, or health services use) imply that the direct cost of incontinence is high [22–24]. These data typically indicate that the majority of direct costs are attributable to routine care (e.g., toileting assistance, absorbent pads, protection, laundry) [23, 25], with staffing

being especially costly [26].

For example, an Australian study used a daily log sheet with hourly entries made by ward staff over 21 days to examine the direct costs of urinary and faecal incontinence in patients in a geriatric rehabilitation or sub-acute neurologic unit [26]. The researchers found that the median cost of dedicated continence care was AUD50 per patient per day, which amounted to about 12.3% of total costs per single room inhabitant and 20.7% per double room. Approximately 85% of this cost was attributed to staffing, with the remaining 15% attributed to consumables and laundry. During a 24-hour period, almost two hours of staff time were dedicated to providing toileting assistance and changing incontinence pads, bedding, clothing, and catheters.

These data provide some indication as to the considerable cost of staffing and other routine care; however, their usefulness in understanding costs in community rehabilitation settings for ABI is limited for several reasons. First, staff assistance required to care for continence-related problems following ABI may differ from that required in geriatric and general neurologic rehabilitation settings. Second, there are substantial additional costs associated with community rehabilitation services that are not required within sub-acute settings, such as the need to employ additional staff to provide care and the need to travel to client homes. Therefore, cost data in the ABI population using community rehabilitation services are needed to provide a proper analysis of the cost-effectiveness of current and future service delivery and practices.

## 2.3 Impact on Health-Related Quality of Life

Incontinence following brain injury is associated with some physical consequences, including reduced skin integrity and risk for urinary tract infection [27]. However, the burden of incontinence is multifaceted, extending beyond the physical to severely affect an individual's quality of life. Although there is no universal consensus as to the definition of quality of life, the World Health Organization (WHO) defines quality of life as:

“...an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.” [28]

This definition highlights that quality of life is influenced by many factors and is the product of a person's subjective experience. Health-related quality of life (HRQOL) focuses specifically on a person's subjective experience of their physical, cognitive, emotional, and social health [29]. Therefore, it is a useful term when considering and describing a person's complex and multidimensional experience of their health.

Many studies have demonstrated the general quality of life impact of continence problems in non-ABI populations [30, 31]. However, the impact of continence problems, specifically in the ABI population, has not been well characterised, which makes it difficult to estimate the actual impact in this population. Of the research that has been conducted in the ABI population, most has been conducted on stroke survivors with urinary incontinence. These studies indicate that continence problems are associated with significantly worse outcomes in HRQOL [11, 32, 33]. Most studies also report that this relationship is independent of other prognostic and demographic factors, although there are exceptions (e.g., Sturm et al., 2004 [34]).

The impact of urinary incontinence on survivors of stroke can be greater than on people who experience incontinence from other causes [11]. For example, a study that used a community-based survey to examine the specific impact of urinary symptoms (e.g., leakage several times per month) on the lives of stroke survivors found that stroke survivors were more likely to report a negative impact of urinary symptoms on their lives compared with the non-stroke population with urinary symptoms, even after controlling for age and sex [11]. In the stroke sample, 12% reported that their urinary symptoms affected their quality of life “a lot” compared with only 4% of the non-stroke sample. Even relatively mild symptoms of incontinence may affect quality of life. Edwards and colleagues used a sample of stroke survivors living in the community six months post-stroke to determine the point at which involuntary urine loss is associated with poorer quality of life [32]. The researchers found that stroke survivors who reported just one episode of involuntary urine loss per month had worse quality of life (measured using the Short-Form 12 Health Survey [SF-12]) than those who reported no involuntary urinary loss [32].

Research has also examined the impact of incontinence on specific domains of HRQOL, with some studies reporting that continence problems are linked to poor perceptions of physical health. A large population-based, cross-sectional study examined the independent predictors of HRQOL (as measured using the Short-Form 36 Health Survey [SF-36]) one and three years after stroke [33]. After accounting for demographic factors (e.g., age, gender, ethnicity, socioeconomic status) and prognostic indicators (e.g., premorbid functioning, laterality of stroke, comorbidity), urinary incontinence was a significant independent predictor of stroke survivors' subjective experience of physical health (e.g., bodily pain, general health, physical functioning) one and three years after stroke. In qualitative studies, survivors

of stroke have described the physically unpleasant effects of incontinence in terms of bed wetting, wet clothing, skin discomfort, and the effects on skin integrity [35].

There is some evidence from quantitative research that continence problems are associated with poorer HRQOL in the domains of psychological wellbeing, especially depression. Brittain et al. [36] undertook a community-based survey with a random sample of the Leicestershire population older than 40 years to determine the relationship between stroke, incontinence, and depression. After controlling for age and sex, the researchers demonstrated that self-reported depression after stroke was 2.4 times more likely in patients with urinary dysfunction than those without. The prevalence of depression was higher in stroke survivors with urinary dysfunction (32%) than the non-stroke population with urinary symptoms (22%) and stroke survivors without these symptoms (15%). More recently, a cross-sectional study found that urinary incontinence was statistically associated with depression one year after stroke, even after taking into account factors such as no vocation, having a caregiver, and complications at discharge [37].

Qualitative studies have also reported a variety of negative psychological and social effects. Stroke survivors describe feelings of disgust, shame, lack of confidence, altered self-esteem, low mood, anger, worry, frustration, embarrassment, and depression [35, 38–40]. Many also report a sense of powerlessness, loss of self-agency, and belief that nothing can be done to improve their current situation [35]. Negative social consequences of continence problems include concerns about the impact of continence problems on intimate relationships and friendships [35, 38], and the restriction of social activities and isolation due to feelings of embarrassment [38].

Limited research has been conducted to understand the relationship between faecal incontinence and HRQOL, with no published studies undertaken in the brain injury population. In this situation, it is helpful to look to evidence from studies conducted with other non-ABI populations [41]. Studies of this kind indicate that more frequent events of losing stools are associated with significantly more impairment in quality of life [42, 43]. There is also some evidence that faecal incontinence has a greater impact on HRQOL than isolated urinary incontinence, with the greatest impairments seen in people with combined urinary and faecal incontinence [44–46].

In summary, there is evidence that symptoms of incontinence are associated with impaired HRQOL. However, there are several limitations to the current evidence, which make it difficult to estimate the HRQOL impact caused by continence problems in the ABI population. First, all studies considered only one sub-type of ABI (i.e., stroke), and similar data for other sub-types of ABI (e.g., brain injury from traumatic or hypoxic causes) are lacking. Although the impact of ABI from stroke is often comparable to the impact of ABI from trauma and other causes, accurate and representative data are crucial for determining the true quality of life impact in the ABI population and for planning and delivering effective care. Second, the design of studies was predominantly cross-sectional [11, 33, 37, 42, 43], which prevents inferences of causation. Third, no studies examined the impact of faecal incontinence in samples of people with ABI, even though this form of incontinence is highly prevalent and has been associated with the greatest impairment in other populations [44–46]. Given the high prevalence of continence problems in this vulnerable population, these limitations indicate an urgent need for greater research on this topic in order to provide effective, cost-efficient care to minimise the negative impact of continence difficulties on HRQOL.

## 2.4 Impact on Functional Outcomes

In addition to the impact on HRQOL, incontinence following brain injury has been associated with loss of independence, higher rates of admission to health services following acute care, and increased risk of mortality [4, 7, 32, 33, 47–53]. In many cases, this relationship is independent of other prognostic factors. For example, a study that investigated the association between urinary incontinence and independence in stroke survivors found that persistent urinary incontinence was associated with worse outcomes after controlling for age, gender, and stroke type [52]. Edwards and colleagues [32] interviewed 361 individuals six months post-stroke to investigate the impact of urinary incontinence on reintegration into home and community living. Stroke survivors with urinary incontinence reported reduced reintegration to normal living compared with those without incontinence, even after controlling for demographic factors and other indicators of stroke severity (i.e., impairment of motor and cognitive functions). On average, survivors with incontinence retained only 40% of their pre-stroke activities, whereas continent individuals retained 70%.

Incontinence has also been linked to higher rates of admission to health services following acute care [6, 7, 52]. Patel and colleagues [52] examined the association between admission to health services and urinary incontinence. After accounting for age, sex, medical history, complications, initial impairments, and functional status, the researchers found that incontinence three months post-stroke was independently associated with an increased risk of being in residential care; approximately one in three survivors with urinary incontinence were in care compared to fewer than one in ten survivors without urinary incontinence. At 12 months post-stroke, up to 45% of stroke survivors with urinary incontinence were estimated to be in care [6]—a fourfold higher risk compared to those without urinary symptoms.

Other studies have demonstrated that post-stroke urinary incontinence is independently associated with higher mortality rates [54, 55]. For example, one study demonstrated significantly higher mortality rates in patients who had incontinence at one week, six weeks, and 12 months compared to those with normal voiding. The researchers also reported that those who regained continence within the first week had a similar prognosis to those with normal bladder control. This was also demonstrated by Barer and colleagues [49], who reported that those who regain or remain continent have better outcomes. Consequently, the researchers stated that “recovery of continence may promote morale and self-esteem which could hasten overall recovery.”

Despite the association between incontinence and traumatic brain injury, very few studies have addressed this in the context of independence. Still, there is some indication that relationships evident in the stroke population extend to the traumatic brain injury population. For example, Chua, Chuo, & Kong [47] used retrospective reviews of medical charts, nursing input–output charts, and team staffing conferences to examine outcomes of urinary incontinence during acute rehabilitation. The researchers found that urinary incontinence correlated significantly with longer length of stay in rehabilitation (51.8 days vs. 27.3 days), poorer functional status on admission to rehabilitation (27.9 Modified Barthel Index [MBI] vs. 74.5 MBI), lower functional independence at discharge (51.7 MBI vs. 90.9 MBI), and poorer return-to-work status. Other studies have provided evidence that reduced bladder and bowel control are associated with less travel outside of the home [53] and poorer cognitive function [4, 56].

Taken together, these studies indicate that survivors of ABI with incontinence generally experience poorer independence and reintegration to the community. However, it is difficult to determine the

extent to which impaired independence is attributable to continence problems, as there are likely to be several reasons why incontinence is associated with worse outcomes. First, incontinence is a marker of brain injury severity and deficits [4, 41]. Second, incontinence has been independently associated with increased risk for medical complications, including falls, urinary tract infections, and skin break down [57]. It has also been suggested, however, that the devastating impact of incontinence can interfere with an individual's ability to participate in rehabilitation programs [58, 59], such as through interfering with sleep and other activities of daily living. The psychological consequences of incontinence may also lead to poor concentration and reduced motivation to participate in rehabilitation [41]. Therefore, it is possible that recovery from continence problems may remove barriers to participation in rehabilitation and improve psychological functioning, thereby speeding up overall functional recovery [49]. As such, continence status should be considered not only as an indicator of injury severity and other medical complications, but also an important target for intervention and management.

## 2.5 Continence Management

### 2.5.1 Current Practices

Despite the considerable economic and personal burden of incontinence following brain injury, health services research (e.g., Jordan et al., 2011 [60]) often indicates a discrepancy between best practice and clinical care delivery for continence management.

Incontinence has multiple classifications that require individualised management. Additionally, the diversity of factors that influence continence in the brain injury population—including dietary intake, mobility, and communication—require the expertise of a multidisciplinary team. Therefore, clinical guidelines typically recommend the use of individualised programs using a multidisciplinary approach with staff training in continence management, as well as the development of tailored management plans (e.g., *National Stroke Foundation [NSF] guidelines*, 2017 [61]). Some guidelines also include more specific recommendations for continence management.

Although Australian clinical guidelines for the full range of ABI diagnoses were not identified, the guidelines produced by the British Society of Rehabilitation Medicine and Royal College of Physicians for rehabilitation following ABI [62] state that patients who have urinary incontinence should have:

1. An assessment conducted by a professional trained in continence management in the context of ABI.
2. A regular monitoring program (e.g., 24-hour voided volume and fluid intake charts).
3. Access to specialist management and advice, including further investigation.
4. Effective strategies for alerting carers to the patient's need to pass urine in cases of communication and mobility problems.
5. An established toileting regime based on reinforcement in cases of cognitive impairment.

Additional recommendations include that long-term catheters should only be used after a full assessment, and less invasive forms of bladder management have been considered due to their potential for harm (e.g., through infection).

However, current practices in clinical care delivery often fail to meet even the most basic recommendations for assessment and management. In 2008, the first NSF audit of Post-Acute Services in Australia indicated that less than half of stroke rehabilitation sites used assessments for

incontinence [63]. Further, the NSF National Stroke Audit Acute Services Clinical Audit Report found that only one-third of stroke survivors with incontinence had a documented continence plan, and one-quarter had an indwelling urinary catheter inserted within one week of admission [64]. Similar data have been reported in the United Kingdom (UK), with the most recent National Sentinel Stroke Audit Phase II (clinical audit) [65] reporting that less than two-thirds of stroke survivors experiencing urinary incontinence had a management plan documented, and one in ten cases of urinary catheterisation had no clear rationale for the insertion documented.

Where assessments and management plans have been made, gaps between clinical care and best practice have been identified. For example, O'Connell and other researchers [66] evaluated the extent to which 76 different continence assessment resources used in Australian residential aged care settings met international standards for continence assessment. The researchers identified five key limitations of current resources. First, most resources did not meet the standards for assessing voiding patterns and symptoms. Second, some facilities did not make use of bowel and/or bladder chart resources. Third, most resources did not provide cues for the diagnosis, management, or evaluation of incontinence. Fourth, resources with strengths in some aspects of incontinence assessment typically had weaknesses in other areas. Fifth, it was not clear whether resources were appropriate for use by all levels of staff (i.e., from registered nurses to unregulated workers). Although these data were collected from aged care settings, incontinence in the ABI population is at least as prevalent as in aged care [67] but has received considerably less research attention and may be considered a lower clinical priority. Therefore, these data may underestimate the extent of the problem with the assessment of continence in the ABI population.

There is some evidence on the use of management plans in the ABI population. A survey of senior nurses from acute stroke units in Australia found that only half of the management plans (formal and informal) for urinary incontinence had been reviewed against the latest national guidelines. Additionally, a substantial minority (16%) had been developed without any reference to evidence from the literature, which suggests that many formal plans do not conform to current guidelines [60]. Further, only 60% of nurses reported that *any* of their nursing staff had received training in the assessment of patients with urinary incontinence [60].

Providing the best available rehabilitation and management strategies for continence might improve HRQOL and functional outcomes and, ultimately, aid social and community reintegration following brain injury. However, the data reviewed in this report indicate that current continence assessment and management practices are sub-optimal and stand in contrast with clinical practice guidelines. Indeed, continence management was listed as one of the Top Ten Areas for change in the National Sentinel Stroke Audit Phase II, and it was stated that continence management is “an area where major improvements are needed” and that “all patients with continence problems should have a documented plan with evidence” [65]. Specifically, there is a clear need to develop evidence-based continence assessment resources and identify empirically supported methods for continence management in the brain injury population.

### **2.5.2 Evidence-Based Continence Management**

The discrepancy between best practice and clinical care delivery may in part reflect the limited evidence to support clinical guidelines [68]. To date, evidence to underpin the management of incontinence after brain injury is poor [69]. A 2008 Cochrane review of prevention and treatment of urinary incontinence following stroke concluded that there was insufficient evidence to guide practice,

but a structured assessment and specialist continence nursing would likely reduce rates [69]. Notably, a research evaluation of the potential impact of management on quality of life and thus independence is also lacking.

In this situation, general principles and research in the universal treatment and management of incontinence should be examined [41]. Research of this kind provides some evidence that different continence management methods are associated with different levels of HRQOL. For example, Liu and colleagues [70] used a cross-sectional research design to investigate the relationship between different bladder management methods and HRQOL in 142 outpatients with spinal cord injury—a condition that commonly co-occurs with ABI—at the Spinal Cord Injury Centre in the UK. The researchers examined several management methods, including normal voiding, bladder reflex voiding, bladder expression, clean intermittent catheterisation by either self-catheterisation or catheterisation by an attendant, indwelling catheter (transurethral or suprapubic), sacral anterior root stimulation, and non-continent urinary diversion/ostomy.

The researchers [70] found that patients who needed clean intermittent catheterisation or indwelling catheters reported poorer personal relationships and emotions than those who reported normal voiding and individuals using other methods, such as bladder reflex triggering. This indicates the possibility that conservative management (i.e., non-pharmacological and non-surgical) is associated with better emotional and social functioning than management that is surgical and invasive. Notably, those who had clean intermittent catheterisation performed with the assistance of an attendant rather than independently reported the lowest HRQOL in the domain of emotional functioning. Therefore, continence management that is conservative and preserves independence may be associated with better emotional functioning and personal relationships than management, which relies on assistance from others.

The possibility that certain management methods that preserve independence positively impact HRQOL is supported by additional research. For example, one study demonstrated that people who are unable to perform self-catheterisation independently have a 4.6-fold increase in their risk of depression compared with individuals who were able to perform self-catheterisation. Further, a recent systematic review of the relationship between neurogenic bladder management methods and quality of life among individuals with spinal cord injury concluded that individuals who were more dependent on others for voiding might experience a lower quality of life than those who are independent [71]. This is also consistent with evidence that the locus of control has an important impact on an individual's quality of life [72]. Thus, being dependent on others to aid in voiding/defecating could contribute to a lower quality of life, which may, in turn, affect a person's independence and rehabilitation outcomes.

For instance, one study [73] used a sample of community-dwelling individuals older than 60 years to examine the impact of delayed versus immediate conservative management on urinary incontinence and quality of life. To investigate this, participants were randomly assigned to receive either immediate (experimental group) or delayed (comparison group) management. After four months, continence was restored, and incontinence improved in 25% and 63% of individuals who received immediate and delayed management, respectively. Compared to quality of life before the start of the intervention period, people who received immediate intervention reported statistically significant improvements in quality of life, including in the domains of depression ( $p < 0.001$ ), isolation ( $p < 0.03$ ), embarrassment ( $p < 0.001$ ), laundry ( $p < 0.001$ ) and smell ( $p < 0.02$ ). Additionally, the researchers could largely rule out

the possibility of a placebo effect, as evidenced through comparison with the delayed intervention group, which did not see the same extent of improvement.

Support for the finding that invasive or surgical management is associated with poorer HRQOL is more mixed. At least one study provides some support for this finding. Using a sample of patients with Spina Bifida, Lemelle and other researchers [51] found that surgical management for urinary incontinence was not associated with better HRQOL than other bladder management techniques. However, a 2006 review of interventions for neurogenic bladder (commonly reported by persons with ABI [74]) found that individuals who had undergone surgical management reported better quality of life following surgery [75].

In summary, research on effective continence management is lacking. However, there is some evidence that conservative management that preserves independence may improve HRQOL. Specifically, conservative management can potentially improve quality of life, especially in emotional and social domains (e.g., depression, embarrassment, isolation) compared to delayed intervention and more invasive, surgical methods. There is also some evidence that individuals who are more dependent on others to aid in voiding may experience a lower quality of life than those who are independent.

### 2.5.3 Assistive Devices

One way to support individual independence in toileting using conservative management may be to minimise staff involvement through assistive devices (ADs), equipment, or technologies (collectively referred to as ADs in this report). ADs can help a person to overcome impairments and activity limitations either by enabling the person to perform tasks they would otherwise be unable to do or increasing the ease and safety with which tasks are completed [76].

A wide range of ADs specifically for the ABI population is described in the literature. These range from simple, low-technology devices (e.g., walking sticks) to complex, high-technology devices (e.g., motorised wheelchairs) [77].

For this project, ADs for toileting and continence were categorised into five main groups according to the type of assistance a person requires:

1. **Mobility devices** to assist people in moving around their environment (e.g., wheelchairs, walking sticks, walking frames).
2. **Cognitive devices** to assist people to remember to complete activities (e.g., electronic devices with prompts).
3. **Positioning devices** to maintain lying, standing, or sitting positions (e.g., wedges, chairs, standing frames).
4. **Daily living devices** to assist people in completing specific toileting activities (e.g., toilet seats, toilet frames, bars, commodes, bidets, bedpans, shower seats, handheld urinals, bottom wipers, handheld urinals).
5. **Vision devices** (e.g., contrasted toilet seat, ping pong ball for visual contrast).

Other aids that help to manage urinary retention (e.g., intermittent catheters, indwelling catheters, drainage bags, catheters, and valves), contain or control urinary incontinence (e.g., pads, bodyworn urinals, sheaths, occlusives, and catheters) or faecal incontinence (e.g., pads, anal plugs, rectal pouches, rectal tubes, and catheters) were categorised as consumable products, as they typically do not increase a person's independence and require recurrent use and frequent replacement.

ADs have the potential to augment or replace some of the tasks undertaken by staff or carers and have been shown to greatly improve treatment outcomes for individuals with ABI [77], as they provide a means for individuals to regain independence, self-determination, and autonomy. Therefore, ADs have the potential to reduce care hours and thus expenditure [78]. In the ABI population, studies have shown that ADs can facilitate independence in activities of daily living such as cooking [79], dealing with getting lost [80, 81], budgeting [82], social and functional communication [83, 84], and planning daily routines [85–87].

Currently, the effectiveness of ADs for toileting assistance has not been empirically documented. Further, many persons with ABI may not use or even be aware of ADs to support toileting. For example, a recent study conducted in Victoria, Australia found that only 34.5% of persons with ABI in shared supported accommodation made use of *any* electronic ADs [88]. Consequently, the potential impact of ADs on toileting and continence-related costs, HRQOL, and independence is poorly understood.



# 3

## Goals of the Current Project

Problems with continence are common in people with an ABI. Yet continence remains poorly assessed and significantly under-managed in this population. Adequately managing continence may not only improve rehabilitation outcomes and increase independence but significantly reduce the burden on the healthcare budget.

Current research on continence management suggests that conservative (i.e., non-surgical and non-invasive) management can not only preserve individual independence but also improve quality of life. One way to support independence in toileting using conservative management is to minimise staff involvement by using ADs. However, research has yet to examine this possibility in the ABI population. Moreover, little is known about current organisational and staff practices in continence management in Australian brain injury rehabilitation facilities.

This report describes a project designed to trial the use of ADs for continence/toileting in people with an ABI. The project aimed to decrease the cost of care, increase independence, and improve quality of life for clients with ABI receiving staged, community-based injury rehabilitation at Brightwater.

The project had four primary objectives:

1. Investigate, review, and trial technology to support people to toilet more independently.
2. Identify opportunities for change in practice (i.e., increase independence, decrease staff intervention).
3. Determine the change in quality of life for residents using assistive toileting technologies.
4. Provide a final report and recommendations to the Insurance Commission and Brightwater.



# 4

## Methodology

### 4.1 Project Design

The preliminary study used a mixed-methods approach to investigate the use of ADs for 16 people with an ABI and continence/toileting difficulties receiving community-based brain injury rehabilitation.

The project was conducted by Brightwater Care Group (WA) and began as a prospective cohort study. However, during the study, it became evident that the initial focus on ADs was too narrow. The research team observed that current staff and organisational practices in continence care could be improved. Therefore, the rationale for using a mixed-methods approach was to expand the study focus and strengthen the conclusions and recommendations through verification from multiple data sources.

The sample of 16 clients was considered acceptable in order to test the feasibility of the proposed intervention due to the: (1) limited number of clients at participating research sites who met the eligibility criteria, (2) funding available for the research, and (3) length of the study period. This preliminary research can be scaled up should research using larger samples be required to further examine the study concept and/or findings.

All study procedures adhered to the guidelines from the Australian *National Statement on Ethical Conduct in Human Research* [89]. All data were de-identified and collected with the express purpose of improving service provision and care. The analysis of this routinely collected data is classed as service evaluation, which does not require ethical approval for research in Australia.

Consent was obtained for all clients included in this study. A dedicated admissions team at Brightwater have a series of interactions with prospective residents (who have an ABI) and their families prior to admission. During this process, consent is obtained for the use of client information as de-identified data in the future. In cases where the client is unable to give informed consent due to reduced cognitive or communicative capacity, consent is given by a legal guardian on their behalf. Members of the admissions team do not have any involvement in subsequent clinical care and were not involved in the current research.

A significant portion of ABIs and strokes causing ABIs are caused by motor vehicle accidents.

## 4.2 Setting

Brightwater Care Group (WA) provides staged community-based brain injury rehabilitation for people aged 18–65 years living with an ABI in Perth, WA. Admissions are accepted at any time after the injury, and rehabilitation takes place either at a community-based residential facility or offsite in the person's own home.

The current study was conducted at two Brightwater brain injury rehabilitation sites: Oats Street and Marangaroo. The purpose-built Oats Street facility comprises 43 residential beds: eight small group houses (4–6 clients per house), eight independent living units, and 15 residences for clients living in their home environment. The facility is designed so that all stages of post-acute rehabilitation can occur at the one site, ranging from stage 1 (full assistance and 24-hour care) to stage 10 (full independence). The residences embody this staged approach to rehabilitation, with each providing different levels of assistance to appropriately support clients' physical, sensory and care needs, and to facilitate progressively greater levels of independence. On admission, clients are assigned to the most appropriate residence according to their stage and move through residences as they progress towards independence.

Marangaroo offers two rehabilitation programs: Discovery Way and Endeavour House. Discovery Way is a shared community housing environment for clients with ABI that supports clients to meet their care and rehabilitation goals while appropriate, sustainable long-term accommodation is sourced. Once appropriate long-term accommodation is available, Brightwater gives the client and their family support and assistance to transition to this accommodation. Endeavour House provides accommodation for 18 young people with ABI who require moderate to high levels of care and are seeking longer term accommodation.

The Insurance Commission provides funding for the care of some clients receiving rehabilitation services from Brightwater.

## 4.3 Participants

### Clients

Participants were 16 clients with an ABI and continence/toileting difficulties enrolled in the Brightwater community rehabilitation service. Eligibility criteria were an ABI of any cause (i.e., traumatic such as a motor vehicle crash, stroke, or hypoxia) and continence and/or toileting difficulties. Clients who were identified by clinical staff as being inappropriate to participate due to behavioural concerns were excluded from the study to reduce emotional distress to clients, families, and staff. Clients who met the eligibility criteria were approached at the participating Brightwater sites and invited to participate in the study. Consent for the use of de-identified data was obtained for all clients included in this study.

### Staff

In addition to clients, allied health, nursing, and disability support staff who were directly involved in the clinical care of clients at Oats Street and Marangaroo were invited to respond to a brief continence survey. Of the 47 staff invited to participate, 24 responded to the survey.

## 4.4 Intervention

The intervention comprised:

1. Contenance assessment.
2. Development and implementation of continence management plans.
3. Trial of ADs.

Each component of the intervention is detailed under the relevant sub-heading.

### 4.4.1 Contenance Assessment and Management Plans

#### Contenance assessment

All participants underwent a continence assessment prior to selecting and trialling ADs. Contenance assessments were conducted using a continence assessment form created for this project. Form development was informed by reviewing assessment tools used by other organisations involved in continence assessments, the findings of empirical research, and current best practice guidelines.

Contenance assessments comprised:

1. **General factors:** cognitive and communicative capacity; impact on quality of life symptoms; brief history of previous investigations, treatments, and management strategies; current use of any consumable products and/or ADs.
2. **Clinical symptoms:** bladder and bowel frequency, timing, and volume; circumstances of voiding and emptying the bowel; any complaints, signs, and symptoms of urinary and faecal incontinence.
3. **Non-specific contributing factors:** medical and surgical history, obstetric/gynaecological history, sexual symptoms, general information (e.g., pelvic floor function, exercise, sleep patterns, stress and relaxation, and medication), physical conditions (e.g., skin conditions, urogenital inspections), mobility, current medications.

Clinical interviews were conducted with each client to complete continence assessments. To determine the accuracy of the information obtained during the clinical interviews, each client's care team was consulted. Additionally, clinical documentation (i.e., progress notes, admission and discharge documents, previously completed outcome measures, bowel charts, team emails, and care plans) was reviewed to ensure a comprehensive understanding of each client's continence difficulties.

#### Contenance Management

Outcomes of continence assessment were used to individually tailor management to each client's specific needs and preferences.

Management plans included the following new and ongoing strategies and information:

1. Level of assistance and number of staff required to support toileting (e.g., independent, supervision, prompting, reminding, directional support).
2. Clients' preferences for continence care during the day and night.
3. Toileting program (e.g., prompted routine with staff assistance, including toilet position for bladder and bowel).
4. Pad check/change program (including number and size of pads).
5. Mobility devices for toileting (e.g., walking frame, hoist).
6. Other ADs for toileting (i.e., cognitive, vision, positioning, and daily living devices).
7. Pain management techniques.
8. Sleep management (e.g., night light, positioning devices).

9. Fluid intake and dietary changes.
10. Laxatives, suppositories, and aperients (type, dosage).
11. Other treatment options (e.g., medication, bladder training, electrical stimulation, pelvic floor muscle training).

To ensure that the management plans were implemented, the research team collaborated with appropriate clinical staff members. The research team provided clinical staff with recommendations for continued care to encourage continued best practice upon completion of the study.

#### **4.4.2 Assistive Devices Trial**

The selection of ADs to trial for each client was determined by the outcomes of the continence assessment. To ensure a client-centred and multidisciplinary approach was adopted throughout the trial, clients, their families, and staff were consulted.

For this project, the cost and complexity of devices could range from inexpensive and low-technology devices (e.g., bottom wipers) to costly and high-technology devices (e.g., bidets). Table 1 summarises the key ADs planned for trial during the study.

Consumable items such as pads and disposable bed protectors were included as part of standard management routines as required; however, these items were *not* classified as ADs, as such items do not increase client independence nor do they typically reduce the need for staff or carer intervention (e.g., a staff member is often still required to change continence pad).

Clients were educated on how to use their allocated ADs, and step-by-step user instructions were also placed in client bedrooms. Education was provided to nursing, allied health, and disability support staff. Staff members were notified as to which clients were using new ADs via email, through the use of the site communication book, and during daily handover. Researchers were also present at clinical meetings to inform the team of these new devices.

Table 1. Assistive Devices

Device	
<b>Wristwatch</b>	Wristwatches were trialled for clients (n=3) with cognitive deficits who required a regular toileting regime with prompted voiding. A “toilet” alarm was programmed on the wristwatch for waking hours. Alarms were set at three or four hourly intervals according to the client’s toileting regime.
<b>Bidets</b>	<p data-bbox="557 495 1399 595">Bidets were considered for clients (n=2) who required physical assistance to maintain perineal hygiene. These two clients had an appropriate level of balance and dexterity to use the bidet effectively.</p> <p data-bbox="557 622 1399 831">However, Brightwater was unable to install the selected bidets as they did not meet specific legislation from the Plumbers Licensing Board of WA. Namely, bidet installation was not possible due to the Back Flow Prevention to Australian Standards Certificate. To install the model of bidet in WA, plumbing regulations require a Reduced Pressure Zone device to be installed at each point of use.</p>
<b>Long-handled bottom wiper</b>	Long-handled wipers were trialled for clients (n=4) who experienced difficulties managing perineal hygiene due to a reduced range of movement or reduced balance.
<b>Visual aids</b>	<p data-bbox="557 985 1399 1167">A visual aid was trialled for one participant with a visual impairment. This participant experienced a right-sided inattention (requires promoting to redirect to his right side) and left-sided hemianopia (unable to see any of his left visual field) as a result of a right posterior cerebral artery infarct, meaning a significantly reduced visual field.</p> <p data-bbox="557 1193 1399 1328">The participant preferred to stand while urinating but had difficulty seeing the white toilet bowl against the white wall due to lack of colour contrast. Therefore, an orange ping pong ball was placed in the toilet bowl to give a colour contrast against the toilet bowl to assist with aim while urinating.</p>
<b>Non-spill bottle</b>	Non-spill bottles were provided to male clients who experience urgency, or have difficulties reaching the toilet in a short period, particularly overnight.

## 4.5 Researchers

Data collection was completed by two clinical staff at Brightwater—a continence Physiotherapist and Occupational Therapist working with people with ABIs.

## 4.6 Intervention: Data Collection and Procedures

Demographic and diagnostic data were extracted from participants' case notes at baseline (Time 0). Quantitative outcomes were collected using three tools:

1. Functional Independence Measure + Functional Assessment Measure (FIM + FAM) [90].
2. Northwick Park Care Needs Assessment (NPCNA) [91, 92].
3. Quality of Life after Brain Injury (QOLIBRI) [93, 94].

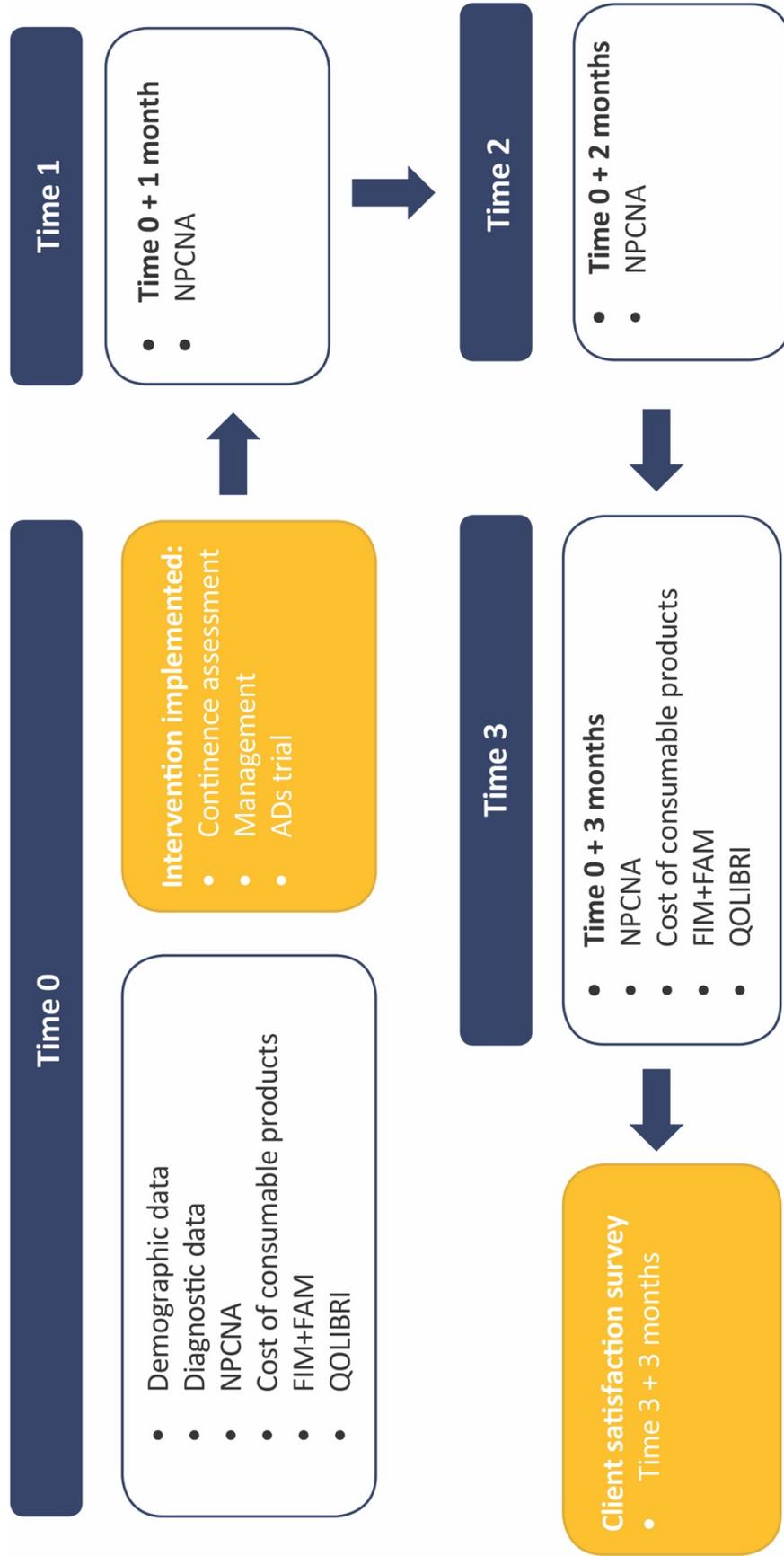
Within the Brightwater community rehabilitation service, all clients are routinely assessed on these measures at admission and again on review and/or discharge. The tools are applied by the multidisciplinary team, and regular formal training is provided for all staff in these instruments. For the current analysis, NPCNA data were collected by the clinical research team at four time points at four weekly intervals (Time 0, 1, 2, and 3). FIM+FAM and QOLIBRI data were collected at two time points (Time 0 and Time 3).

In addition to these validated tools, the cost of consumable products per client was estimated at Time 0 and Time 3. Three months after completion of the initial research project, clients who were still receiving rehabilitation at a Brightwater site and had been allocated ADs as part of the intervention were also asked to respond to a brief client satisfaction survey.

Figure 2 provides a summary of each of the data collection times, including tools and measures collected at each time point. A summary of information regarding when continence assessments were conducted and when management plans and ADs were implemented is also provided in Figure 2. Clients continued to use ADs implemented as part of the trial after completion of the study period if required and if they were satisfied with the device.

Given the sensitive nature of some of the questions asked during the study (e.g., the QOLIBRI contains items assessing feelings of anxiety, anger, and depression), researchers forwarded copies of completed QOLIBRI scales to site social workers upon request. This was done to ensure appropriate follow-up and support could be provided to clients who were at risk of emotional distress.

Figure 2. Study Timeline and Data Collection at each Time Point



### 4.6.1 Demographic and Diagnostic Data

Demographic (age on admission) and diagnostic data for the sample were collected from admission and electronic case notes. Diagnostic data included time since injury (years) and length of stay at the Brightwater facility (weeks), in addition to brain injury diagnosis. For this analysis, clients were classified into three diagnostic groups: stroke, traumatic brain injury, and hypoxic brain injury. Table 2 gives information on client-specific brain injury diagnoses and the categories applied for the present study.

**Table 2. Client Diagnoses Mapped on Diagnostic Categories**

Study classification	Client diagnosis
Stroke	Sub-arachnoid haemorrhage
	Left middle cerebral artery stroke
	Left pontine haemorrhage
	Left intraventricular haemorrhage
	Right posterior cerebral artery stroke
	Right internal capsule infarct
Traumatic brain injury	Brainstem cerebrovascular accident
	Assault
	Motor vehicle accident
Hypoxic brain injury	Overdose
	Hypoxic ischaemic encephalopathy
	ABI secondary to hypoglycaemic coma

### 4.6.2 NPCNA: Northwick Park Care Needs Assessment

The NPCNA tool provides a directly costable measure of care needs and is derived from the Northwick Park Dependency Scale (NPDS). The tool enables an estimate of dependency, care needs, and care costs in community rehabilitation settings for people with an ABI [91, 92]. In this study, the tool was used to estimate the change in care hours per week and weekly cost of care required to fulfil the basic and nursing care needs of clients in the community before and after continence/toileting intervention and provide an estimate of client dependency.

The NPCNA tool has several functions. First, the NPCNA provides an estimate of staff time taken to provide assistance [95]. Second, the tool provides an estimate of direct care costs [91, 95]; therefore, the tool can be used to evaluate the cost-efficiency of intervention by comparing the cost of care per week before and after intervention. Third, clients with high levels of dependency may fall below the lower limits of the FIM, and the NPCNA is more sensitive to change for clients with high levels of dependency.

The NPCNA comprises three major sections: (1) Basic Care Needs, (2) Special Nursing Needs, and (3) Care Needs Assessment [93, 94]. Basic care and special nursing needs are derived from Sections 1 and 2 of the NPDS. Basic care needs are assessed using 12 items scored on an ordinal scale ranging from 0

to 5 (e.g., transfers, bladder management, mobility). Special nursing needs (e.g., tracheostomy management, wound care) are assessed using seven items scored dichotomously from 0 (nursing need not required) to 5 (nursing need applicable). A total NPDS dependency score is computed by summing item scores from both sections, with a maximum total score of 100 (i.e., complete dependency). Total scores can be used to categorise clients into levels of dependency (low, medium, high). For this study, clients were categorised as low (NPDS score < 10), medium (NPDS score 10–25), or high (NPDS score >25) dependency. This categorisation is consistent with the categories used in previous research [96].

The NPDS was initially designed to assess client care needs in inpatient rehabilitation [91, 92]. When used as part of the NPCNA, it gives a general assessment of care needs in the community [92]. The NPCNA is derived from the NPDS using a computerised algorithm based on a set of validated assumptions (e.g., if help is required to eat, the assumption is that this will occur three times a day, help will be provided by one person, and the time required at each meal time will be ¼–1 hour), together with an additional five questions designed to directly assess care needs in the community setting (e.g., making a meal).

The computerised algorithm produces outputs including an NPDS dependency score, estimation of staff hours, and cost of care required to meet care needs. The NPCNA produces two outputs for care hours: 'Total Care Hours' and 'Restricted Care Hours'. Total care hours are estimated by summing all allocated time entered into a client's timetable of care. Total care hours do not take into account that many activities are completed simultaneously in practice, and therefore, the time taken is often much less. To overcome this, restricted care hours are estimated. Restricted care hours apply a cap of a minimum of 30 minutes to a maximum of two hours. Evaluations have demonstrated the reliability and validity of the NPDS and NPCNA [91, 97].

In this study, total care hours are used for analyses of care activities specifically for **continence and toileting**, as they represent the actual time taken to complete continence and toileting activities (i.e., many clients required less than 30 minutes for toileting assistance and therefore restricted care hours overestimated care hours and cost). For analyses of **all care activities** (i.e., not only those required for continence/toileting), restricted care hours were analysed rather than total care hours, as they are more reflective of actual care practices by taking into account that many care activities are completed simultaneously (e.g., staff assisting one client while instructing another client).

In this study, the NPCNA algorithm was adapted to ensure cost estimates were relevant to a WA disability and health services context. To do so, cost estimates were converted from UK Pounds to Australian dollars (AUD) and derived from the current National Disability Insurance Agency (NDIA) published price guide (specific to WA, Australian Capital Territory, Northern Territory and South Australia; see Appendix 1: Costing for Valuation of Care) [98].

NPCNA data were collected four times throughout the study: once before the implementation of ADs as a baseline measure (Time 0) and three times post-implementation to monitor changes over time (Time 1, Time 2, Time 3). Given the small number of clients included in the study, only NPCNA data collected at Time 0 and Time 3 are reported. Several methods were used to provide inputs to the NPCNA scales for each client. First, Brightwater allied health, nursing, and disability support staff were consulted. Second, client care plans and progress notes were reviewed. Third, discussions with clients themselves were used when deemed appropriate.

### 4.6.3 Cost of Consumable Products and Assistive Devices

The cost of consumable products required during 24 hours of care was estimated at Time 0 and Time 3 to examine whether this changed over the study period. Clinical staff were consulted to estimate the products required over 24 hours of care, and unit costs were obtained from Brightwater site inventories and suppliers. Consumables included products for managing continence (e.g., pads, pull-ups, drainage bags, and catheters), maintaining hygiene (e.g., wipes), protecting skin integrity (e.g., barrier creams), and those required during staff intervention (e.g., examination gloves, aprons, shoe covers). Supplier costs for consumable products used to compute estimated total costs for the study population are provided in Appendix 3: Cost of Consumable Items.

To estimate the change in costs of ADs after intervention, the costs of ADs at Time 0 and Time 3 were also estimated. ADs included items required for transfers (e.g., wheelchair, hoist), assisting with balance (e.g., grab rail), maintaining hygiene (e.g., long-handled shower sponge, bottom wiper), sitting on the toilet (e.g., over-toilet frame), and dressing (e.g., dressing aids), in addition to devices for behavioural intervention (e.g., wristwatch alarm for prompted voiding). All costs are expressed in AUD.

### 4.6.4 FIM+FAM: Functional Independence Measure + Functional Assessment Measure

The FIM+FAM [90] tool was used to assess the changes in functional independence over the study period. The FIM+FAM is a widely used and well-established measure designed to assess the degree of client independence in day-to-day activities within inpatient rehabilitation settings [99, 100]. Specifically, the measure assesses physical and cognitive disability in relation to the burden of care [101].

The FIM component of the tool comprises 18 items that fall within two domains: motor (13 items; e.g., eating, transfers, toileting) and cognitive (5 items; e.g., memory, orientation, problem-solving). The FAM scale was developed to augment the original FIM scale to improve its utility specifically for the brain injury population [102]. Thus, the FAM is not a stand-alone tool, but rather contributes 12 additional items. FAM items relate to cognitive and psychosocial functioning, in addition to extended activities of daily living (e.g., meal preparation, financial management, leisure activities) [102, 103].

All FIM+FAM items are rated on a seven-point scale ranging from 1 (total assistance) to 7 (complete independence) [104]. Total FIM+FAM scores are calculated by summing individual item scores, producing a possible score range of 30–210. Subscale scores for cognitive (range: 14–98) and motor (range: 16–112) domains are calculated by summing item scores relevant to each subscale. Higher FIM+FAM scores represent a greater level of independence. Training and certification in the administration of FIM+FAM are required to ensure high levels of inter-rater reliability [101]. The FIM+FAM has good psychometric properties, with a highly acceptable level of internal consistency for the total, cognitive, and motor subscales [105, 106].

In this study, the scale was administered twice in order to monitor changes in motor and cognitive performance over time: at baseline (Time 0) and three months after implementing individualised toileting ADs (Time 3).

#### 4.6.5 QOLIBRI: Quality of Life after Brain Injury

Quality of life assessments are an important element of assessing the effectiveness of intervention [107]. In this analysis, the QOLIBRI tool was used to assess quality of life, as it provides a specific assessment of quality of life after brain injury [93]. The self-report measure comprises 37 items designed to capture a client's subjective life satisfaction, which can be used alongside objective clinical indicators (e.g., the FIM+FAM) to give a holistic description of client function [108].

The measure includes six subscales: cognition, emotional view of yourself, independence and daily life function, social relationships, feelings, and physical problems. Clients rate items pertaining to cognition, emotions, independence and daily function, and social relationships on a five-point Likert scale ranging from 1 (Not at all satisfied) to 5 (Very satisfied). Items pertaining to feelings and physical problems are rated on a five-point scale ranging from 1 (Not at all bothered) to 5 (Very bothered), and reverse scored before computing global and subscale scores [108]. To calculate global and subscale scores, responses are summed and then divided by the number of responses to give a scale mean, which are then converted to a 0–100 scale by subtracting 1 from the mean and multiplying by 25. This produces scores with a minimum value of 0 (worst possible quality of life) and a maximum value of 100 (best quality of life). The scale has sound psychometric properties, with demonstrated internal consistency and test–retest reliability [94].

To interpret any quality of life measure with validity, individuals must have an appropriate level of communicative (i.e., verbal, written, or gesture) and cognitive capacity to give accurate responses to scale items [109]. However, some clients with ABI may experience impairments (e.g., deficits in insight and awareness, comprehension, memory, or communication) that prevent them from providing accurate self-report information [109]. In this study, cognitive and communicative abilities were determined by each client's allied health team. Clients who were determined not to have appropriate cognitive or communicative abilities to provide accurate self-report data did not complete the QOLIBRI. As quality of life is experienced subjectively, it was decided that client reports would not be substituted with proxy reports in this study, as these reports can often be inaccurate and problematic to interpret [110].

#### 4.6.6 Client Satisfaction with ADs Survey

Client satisfaction with ADs implemented as part of study intervention was assessed using a brief survey administered by the clinical research assistant. The survey was compiled for this study and included one item to assess client satisfaction rated on a 5-point scale ranging from 1 (Not at all satisfied [with the device]) to 5 (Very satisfied [with the device]). Clients were also invited to provide feedback about their experience of the device. The survey was administered three months after completion of the study; therefore, clients who had been discharged, were deceased, or had not received devices as part of continence management were not able to respond to the survey. Depending on a client's cognitive, communicative, and motor capacity, client responses to the survey were written, verbalised, or gestured.

## 4.7 Current Practices in Continence Management: Data Collection and Procedures

Current staff and organisational practices in continence care were examined using two methods:

1. Qualitative observation.
2. Staff surveys.

### 4.7.1 Qualitative Observation

The clinical research team used qualitative observational methods to record observations made throughout the study that were not captured by other research methods. Qualitative observation is a form of naturalistic research that involves the systematic and detailed observation of a phenomenon in natural settings [111, 112].

For this study, the clinical research team kept and updated a daily electronic written record from study commencement to completion of the study at Time 3. This record included additional client and staff reports, site policy and procedural information, and other internal and external factors that impacted the project method. Preliminary observations made using this method led to the decision to create a staff survey to formally assess staff members' knowledge of continence and current practices in continence management.

### 4.7.2 Staff Surveys

Three staff surveys were developed to assess staff members' knowledge of continence, in addition to knowledge of and actual on-site assessment and management practices. Three surveys were created for (1) allied health staff, (2) nursing staff, and (3) disability support workers. All surveys contained open- and closed-ended questions. Closed-ended questions were scored on a nominal scale with three points: "Yes," "No," "Unsure." Each survey was developed to reflect different levels of staff knowledge and involvement with continence management. Surveys for nursing staff were most comprehensive, including 27 items (e.g., "Is a continence management plan in use for each client?"). Disability support workers responded to 16 items (e.g., "Do you know what fluids each client is drinking?"), and allied health staff responded to nine items (e.g., "Does each client have a continence management plan/toileting regime?").

## 4.8 Analytic Approach

### 4.8.1 Intervention Data

Data were analysed using Microsoft Excel and the Statistical Package for the Social Sciences (version 21). Summary statistics were run on demographic and brain injury data, as well as results of continence assessment.

#### *Outcome data*

Outcome data (NPCNA, FIM+FAM, QOLIBRI, cost of consumables) at Time 0 and Time 3 were described overall and separately by brain injury diagnosis and level of dependency at baseline (Time 0). Inferential statistics were also computed (described below).

Group-level changes in NPCNA data (dependency scores, weekly care hours, weekly cost of care) from Time 0 to Time 3 were analysed using repeated measures *t*-tests. Two sets of tests were conducted to

examine: (1) changes in dependency, care hours, and cost of care specifically for toileting and continence and (2) changes in dependency, care hours, and cost of care for *all* care activities (i.e., not only those required for continence/toileting). Changes in the estimated cost of consumable products were also analysed using repeated measures *t*-tests.

Changes in functional independence (i.e., FIM+FAM scores) and quality of life (i.e., QOLIBRI scores) from Time 0 to Time 3 were analysed using non-parametric Wilcoxon signed-rank tests. Non-parametric methods were used as both tools are primarily based on an ordinal data structure. Significance tests were conducted to examine changes for FIM+FAM item (toileting), domain, and total scores. To examine changes in QOLIBRI scores, significance tests were conducted for subscale and global scores. To analyse client responses to the satisfaction survey, counts and proportions for response categories were presented, and the feedback described.

For all inferential statistics, statistical significance was set at  $p < 0.05$ . All outcome measures analysed using parametric statistics were screened for univariate outliers using the mean  $\pm$  three standard deviations. No univariate outliers were identified. Cohen's *d* [113] was used to give a standardised measure of effect size for parametric statistics. Effect size estimates were interpreted in accordance with Cohen's [113] guidelines for small ( $d = 0.2$ ), medium ( $d = 0.5$ ), and large ( $d = 0.8$ ).

Descriptive analyses were used to describe changes in NPCNA, cost of consumable products, FIM+FAM, and QOLIBRI scores by brain injury diagnosis and level of dependency at Time 0. Inferential statistics were not computed due to the small number of participants in each group (range: 2–10 clients). Additionally, case examples were produced to demonstrate client-level changes in independence and the need for assistance following the implementation of ADs.

## 4.8.2 Current Practices in Continence Management

### *Qualitative observation*

Qualitative observations made by the clinical research team were analysed using a thematic analysis. To do so, an initial thematic framework for the observed data was developed primarily by reviewing the data. Emerging themes were discussed and revised as necessary.

### *Staff surveys*

Staff surveys included a combination of closed- and open-ended questions. For closed-ended questions measured on a nominal scale (i.e., 'yes', 'no', 'unsure'), counts and proportions for response categories are presented and described. All questions were grouped and described according to pre-defined themes derived from qualitative observation: (1) staff knowledge and practice and (2) communication between staff.



# 5

## Results: Intervention

### 5.1 Demographic and Diagnostic Data

Of the 19 clients with brain injury who were approached and invited to take part in the study, three declined to participate. Of those, two declined due to the nature of the study, and one declined for personal reasons. Those who declined due to the nature of the study voiced that they did not feel comfortable discussing continence issues, despite being recognised by staff as having continence difficulties that could be managed alternatively or more successfully. This resulted in an initial sample of 16 clients.

Of the 16 clients included at baseline, one client passed away at Time 2, and one client was discharged from the service at Time 1. The data from these two clients were included and reported for continence assessment and management. Fourteen clients were included at Time 0 and Time 3; therefore, analyses of quantitative outcome data are conducted using this client group.

Several factors contributed to this sample size, including the limited number of clients at participating research sites who met the eligibility criteria, the funding provided for the research, and the length of the study period. As multiple methods of analysis were used, this sample size was considered acceptable as a proof-of-concept to test the feasibility of the intervention.

Demographic and diagnostic data for the sample are given in Table 3. Age on admission ranged from 24 to 64 years (Mean = 48.1 years, *SD* = 12.9). There were almost twice as many females as males in the sample. The majority of clients had sustained a stroke, with an equal number diagnosed with brain injury from trauma or hypoxia. More than half of the clients were classified as high dependency at baseline (Time 0), with just two classified as low dependency. The median time of admission to a Brightwater site since injury was 23.6 weeks, and the length of stay ranged from 23 to 149 weeks at the start of the study.

**Table 3. Demographic and Diagnostic Profile of the Sample at Baseline**

Parameter	n (%)
Sex	
Female	10 (62.5)
Male	6 (37.5)
Age on admission	
<30 years	3 (18.8)
31–40 years	0 (0.0)
41–50 years	6 (37.5)
51–60 years	5 (31.3)
> 60 years	2 (12.5)
Diagnosis	
Stroke	10 (62.5)
Trauma	3 (18.8)
Hypoxia	3 (18.8)
Dependency (at Time 0)	
Low	2 (12.5)
Medium	5 (31.3)
High	9 (56.3)
	Median ( <i>IQR</i> )
Weeks since injury	23.6 (14.7, 33.4)
Length of stay (weeks)	23–149

**Notes.**

1. *IQR* = interquartile range.

## 5.2 Continence Profile at Baseline

Table 4 shows the primary cause of incontinence for participants. Most of the 16 clients (n=11) had functional incontinence due to decreased mobility despite normal bladder and bowel function. Of these, three had urinary incontinence and eight had double incontinence (i.e., combined urinary and faecal incontinence). Of the remaining five clients, three had impaired awareness incontinence (two experiencing double incontinence and one urinary incontinence). Visual impairments also contributed to incontinence for the client with urinary incontinence. Of the remaining two clients, one had urinary incontinence due to comorbidity (Obese Body Mass Index, Class 3, severe) and one was continent but required staff intervention to assist with getting to the toilet at night.

**Table 4. Continence Profile at Baseline**

Cause of incontinence	Frequency (n=16)	Percentage (%)
<b>Functional incontinence</b>	<b>11</b>	<b>68.8</b>
Urinary incontinence	3	18.8
Double incontinence <sup>a</sup>	8	50.0
<b>Comorbidity</b>	<b>1</b>	<b>6.3</b>
Double incontinence	1	6.3
<b>Impaired awareness</b>	<b>3</b>	<b>18.8</b>
Urinary incontinence	1	6.3
Double incontinence	2	12.5
<b>Continent</b>	<b>1</b>	<b>6.3</b>

**Notes.**

- <sup>a</sup>At Time 0, four of the clients with double incontinence due to functional impairments were catheterised to manage episodes of urinary incontinence.

### 5.3 Assistive Devices Trial

Table 5 shows the cost (AUD) of ADs for each client at Time 0 and Time 3 and gives an inventory of all devices. At baseline, the cost of ADs ranged from \$539.40 to \$24,975.50, with an average cost of \$9,618.29 (*SD* = \$7,730.403; *Median* = \$7,801.65, *IQR* = \$2,768.65, \$16,001.80) per client. The most expensive devices were powered wheelchairs (range: \$5,400.50–\$15,000.00) and hoists (range: \$3,000.00–\$7,671.00), and the least costly devices were long-handled shower sponges (range: \$15.40–\$22.50) and urinal non-spill bottles (\$52.00).

All clients had additional ADs included in management plans following a comprehensive continence assessment at Time 0, which resulted in additional cost. The average additional cost for ADs was \$947.04 (*SD* = \$1,251.80; *Median* = \$292.20, *IQR* = \$92.40, \$2,617.25) per client, with a minimum of \$0.50 (ping pong ball for client with visual impairment) and a maximum of \$2,915.00 (bidet, inclusive of installation cost).

Changes in the cost of ADs following comprehensive continence assessment and management planning were examined by brain injury diagnosis and level of dependency at baseline (see Table 6). Of all diagnostic groups, the cost of ADs was highest for the client with hypoxic brain injury and lowest for clients with traumatic brain injury. The cost of ADs increased for all diagnostic groups, with the greatest increase observed for clients with brain injury from traumatic causes. This cost increase was due to the planned installation of a bidet for one client with traumatic brain injury (client 15). When the study population was separated by level of dependency at baseline, the cost of ADs was lowest for low-dependency clients and highest for high-dependency clients at Time 0. This stepwise trend was also observed at Time 3. The greatest increase in cost was observed for clients (n=5) classified as medium dependency at baseline. Again, this cost increase was primarily due to the planned installation of two bidets for two medium-dependency clients (client 2 and client 15).



Table 5. (Continued) Inventory and Total Cost of all ADs at Time 0 and Time 3 per Participant (incl. Cost Change between the Two Time Periods)

Client	Diagnosis	Time 0			Time 3			Change (AUD)
		Dependency	AD	Total Cost (AUD)	Dependency	AD	Total Cost (AUD)	
4	Stroke	Medium	Wheelchair (powered)	\$7,839.40	High	Wheelchair (powered)	\$10,754.40	\$2,915.00
			Shower commode			Shower commode		
			Flip-down rail			Flip-down rail		
			Long-handled shower sponge			Long-handled shower sponge		
						<b>Bidet (incl. plumber and electrician cost)</b>		
5	Stroke	High	Wheelchair (powered)	\$7,763.90	High	Wheelchair (powered)	\$8,066.90	\$303.00
			Wheeled shower commode			Wheeled shower commode		
			Flip-down rail (double)			Flip-down rail (double)		
			Long-handled shower sponge			Long-handled shower sponge		
						<b>Walking stick</b>		
						<b>Wristwatch alarm</b>		
						<b>Handheld urinal</b>		
6	Stroke	High	Wheelchair (manual)	\$3,133.40	Medium	Wheelchair (manual)	\$2,147.40	\$314.00
			Flip-down rail (double)			Flip-down rail (double)		
			Long-handled shower sponge			Long-handled shower sponge		
			Commode			–		
						<b>Shower chair</b>		
						<b>Wristwatch alarm</b>		
7	Hypoxic	High	Wheelchair (powered)	\$13,590.00	N/A	N/A	N/A	N/A
			Shower trolley					
			Ceiling hoist					

Table 5. (Continued) Inventory and Total Cost of all ADs at Time 0 and Time 3 per Participant (incl. Cost Change between the Two Time Periods)

Client	Diagnosis	Time 0			Time 3			Change (AUD)
		Dependency	AD	Total Cost (AUD)	Dependency	AD	Total Cost (AUD)	
8	Stroke	Medium	Wheelchair (powered) Twin hoist Wheeled commode Long-handled shower sponge	\$14,986.40	Medium	Wheelchair (powered) Twin hoist Wheeled commode Long-handled shower sponge Long-handled bottom wiper	\$15,059.00	\$72.60
9 <sup>b</sup>	Traumatic	Low	Wheelchair (powered) Flip-down rail Urinal non-spill (x2)	\$6,028.50	Low	Wheelchair (powered) Flip-down rail Urinal non-spill (x1) Toilet raise with arms Quad stick Bedside commode	\$6,350.50	\$374.00
10	Stroke	Low	Shower chair 4 Wheel Seated Walker Flip-down rail	\$859.00	Medium	Shower chair 4WSW Flip-down rail Long-handled shower sponge Wristwatch alarm Long-handled bottom wiper	\$1,140.40	\$281.40
11	Stroke	Medium	Wheelchair (powered) Long-handled shower sponge Handheld urinal	\$6,067.40	Medium	Wheelchair (powered) Long-handled shower sponge Handheld urinal Quad stick Over-toilet frame	\$6,327.40	\$260.00

Table 5. (Continued) Inventory and Total Cost of all ADs at Time 0 and Time 3 per Participant (incl. Cost Change between the Two Time Periods)

Client	Diagnosis	Time 0			Time 3			Change (AUD)
		Dependency	AD	Total Cost (AUD)	Dependency	AD	Total Cost (AUD)	
12	Stroke	High	Wheelchair (powered) Shower commode Flip-down rail Long-handled shower sponge	\$11,034.40	Medium	Wheelchair (powered) Shower commode Flip-down rail Long-handled shower sponge	\$11,262.40	\$228.00
13	Stroke	High	Wheelchair (powered) Ceiling hoist Flip-down rail	\$19,048.00	High	Wheelchair (powered) Ceiling hoist Flip-down rail Wheeled commode Ankle-foot orthosis (Night & Day)	\$21,566.00	\$2,518.00
14	Stroke	Medium	Flip-down rail Long-handled shower sponge	\$539.40	Low	Flip-down rail Long-handled shower sponge	\$539.90	\$0.50
15 <sup>a</sup>	Traumatic	Medium	4WSW bariatric Bariatric shower chair Long-handled sponge Flip-down rail	\$1,674.40	Low	4WSW bariatric Bariatric shower chair Long-handled sponge Flip-down rail Long-handled bottom wiper Bidet (incl. plumber and electrician cost)	\$4,688.40	\$3,014.00

Table 5. (Continued) Inventory and Total Cost of all ADs at Time 0 and Time 3 per Participant (incl. Cost Change between the Two Time Periods)

Client	Diagnosis	Time 0			Time 3			Change (AUD)
		Dependency	AD	Total Cost (AUD)	Dependency	AD	Total Cost (AUD)	
16	Stroke	High	Powered wheelchair Tilt-in space high-back shower commode Ceiling hoist	\$11,324.00	N/A	N/A	N/A	

**Notes.**

1. All ADs were purchased only once unless specified under a specific note (as denoted by a superscript letter).
2. ADs implemented following the assessment and implementation of management plans are shown in boldface.
3. ADs used at Time 0 but not Time 3 are indicated with an em dash (i.e., —) at Time 3.
4. All ADs used at Time 0 are included in cost change calculations from Time 0 to Time 3 to provide an accurate representation of cost change between time periods.
5. <sup>a</sup>Client 1 and client 15 had the first long-handled bottom wiper replaced with a second long-handled wiper, as clients did not like the first purchased wiper; therefore, cost calculations are based on the most expensive bottom wiper purchased for each client.
6. <sup>b</sup>Client 9 used two urinal bottles at Time 0 but had reduced to using one urinal bottle at Time 3.

**Table 6. Mean Cost of ADs at Time 0 and Time 3, Separated by Brain Injury Diagnosis and Level of Dependency at Time 0**

	Mean (SD)		Change
	Time 0	Time 3	
<b>Diagnosis</b>			
Stroke (n=10)	\$9,624.68 (8,000.01)	\$10,605.43 (8,857.39)	\$980.75
Trauma (n=3)	\$5,873.43 (4,123.69)	\$6,990.77 (2,680.48)	\$1,117.34
Hypoxia (n=1)	\$20,789.00 (N/A)	\$20,888.00 (N/A)	\$99.00
<b>Dependency (Time 0)</b>			
Low (n=2)	\$3,443.75 (3,655.39)	\$3,745.45 (3,684.10)	\$301.70
Medium (n=5)	\$6,221.40 (5,753.85)	\$7,473.82 (5,600.21)	\$1,252.42
High (n=7)	\$13,808.80 (7,897.39)	\$14,722.10 (8,799.39)	\$913.30

**Notes.**

1. *SD* = standard deviation.

## 5.4 Intervention Outcomes

Change analyses of outcome data were undertaken for the 14 clients for whom full data were available for the NPCNA, FIM+FAM, and consumables data. For QOLIBRI data, analyses were undertaken for the ten clients for whom full data were available.

### 5.4.1 NPCNA: Client Dependency, Required Care Hours, and Cost of Care

#### *Reduction in client dependency in toileting after intervention*

Summing the four NPCNA dependency items relevant to toileting and continence at each time point showed a reduction in client dependency from Time 0 (Mean = 6.4, *SD* = 4.6) to Time 3 (Mean = 5.7, *SD* = 4.1) (see Table 7). This change was accounted for by a reduction in the level of staff assistance required to empty the bladder and bowels, with an observed reduction in Bladder (assistance) and Bowel (assistance) items of 0.4 and 0.2 points, respectively. However, the results of repeated measures *t*-tests showed that these changes were not statistically significant (Table 6). There was no change in mean dependency scores for urinary and faecal incontinence between Time 0 and Time 3.

### Reduction in care hours and cost of toileting assistance after intervention

*After intervention, the estimated weekly care hours for toileting reduced by approximately 4.3 hours per client, which translates to an estimated cost reduction of \$633.29 per client per week.*

Changes in care hours and cost required for toileting are given in Table 7. Before intervention (Time 0), the estimated average weekly care hours required for toileting were 15.3 ( $SD = 9.8$ ) hours per client at an average cost of \$7,249.86 ( $SD = \$6,503.8$ ). After intervention (Time 3), care hours for toileting reduced to an average of 11.0 ( $SD = 8.1$ ) hours per week at an average weekly cost of \$6,616.57 ( $SD = \$4,831.7$ ). This represents a reduction in average care of approximately 4.3 hours per client per week and a weekly cost saving of approximately \$633.29. The results of the  $t$ -tests showed that the reduction in care hours from Time 0 to Time 3 was marginally significant ( $p = 0.079$ ) (see Table 8). The reduction in average weekly cost was not statistically significant; however, the study had low statistical power to detect these effects as significant, given the small sample size. These results

are supported by the results of non-parametric Wilcoxon signed-rank tests (see Appendix 2: Additional Statistical Analyses)

**Table 7. Changes in Continence/Toileting Dependency Scores, Total Care Hours, and Average Cost (AUD) over the Study Period (n=14)**

NPCNA	Time 0		Time 3	
	Mean (SD)	95% CI	Mean (SD)	95% CI
NPDS score				
Bladder (assistance)	2.4 (1.5)	[1.6, 3.3]	2.0 (1.6)	[1.1, 2.9]
Urinary incontinence	0.7 (1.1)	[0.1, 1.3]	0.7 (0.8)	[0.2, 1.2]
Bowel (assistance)	2.6 (1.8)	[1.6, 3.7]	2.4 (1.7)	[1.4, 3.4]
Faecal incontinence	0.6 (1.2)	[-0.1, 1.2]	0.6 (0.93)	[0.1, 1.2]
<b>Total</b>	<b>6.4 (4.6)</b>	<b>[3.7, 9.0]</b>	<b>5.7 (4.1)</b>	<b>[3.3, 8.1]</b>
<b>Care hours/week</b>	<b>15.3 (9.8)</b>	<b>[9.6, 20.0]</b>	<b>11.0 (8.1)</b>	<b>[6.3, 15.7]</b>
<b>Cost/week</b>	<b>\$7,249.86</b> <b>(6,503.78)</b>	<b>[3,494.69, 11,005.03]</b>	<b>\$6,616.57</b> <b>(4,831.72)</b>	<b>[3,826.82,</b> <b>9,406.33]</b>

**Notes.**

1.  $SD$  = standard deviation.  $CI$  = confidence interval.
2. Higher dependency scores reflect greater dependency.

**Table 8. Repeated Measures t-tests with NPCNA Outcomes for Toileting/Continence as Dependent Variables and Time as the Independent Variable (n=14)**

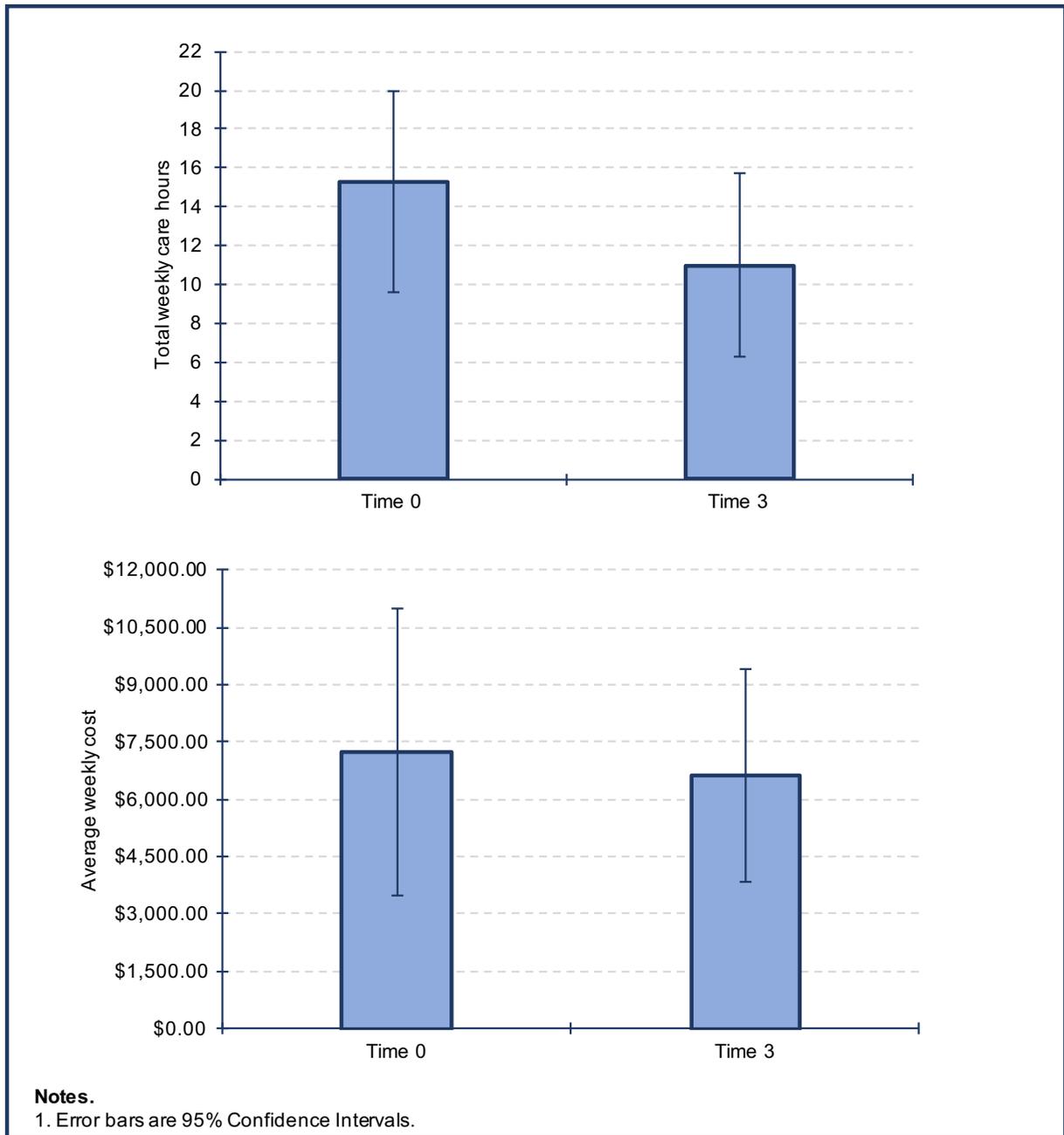
Outcome	Mean difference	t-test		
		<i>t</i>	<i>p</i>	Cohen's <i>d</i>
NPDS score				
Bladder (assistance)	0.4	1.39	0.189	0.26
Urinary incontinence	0.0	0.00	1.000	0.00
Bowel (assistance)	0.2	0.81	0.435	0.21
Faecal incontinence	0.0	-0.22	0.828	0.00
<b>Total</b>	<b>0.7</b>	<b>0.74</b>	<b>0.472</b>	<b>0.16</b>
<b>Care hours/week</b>	<b>4.3</b>	<b>1.91</b>	<b>0.079</b>	<b>0.48</b>
<b>Cost/week</b>	<b>\$633.29</b>	<b>0.44</b>	<b>0.666</b>	<b>0.11</b>

**Notes.**

1. Degrees of freedom = 13. *p* = probability value.
2. Cohen's *d* gives a standardised measure of effect size; effect size estimates were interpreted in accordance with Cohen's [113] guidelines for small (*d* = 0.2), medium (*d* = 0.5), and large (*d* = 0.8).
3. Prior to analysis, skewness and kurtosis of the difference values were examined and deemed sufficiently normally distributed for parametric methods [114].

Figure 3 provides a graphical representation of observed changes in NPCNA data (care hours, cost of care) over the study period.

**Figure 3. Change in Weekly Care Hours and Average Weekly Cost of Care over the Study Period**



### ***Reduction in client dependency, required care hours, and cost of care for all care activities***

Table 9 shows the changes in dependency scores, weekly care hours, and cost for all care activities (i.e., not only those for toileting/continence) from Time 0 to Time 3.

The mean dependency score was 26.9 ( $SD = 18.7$ ) at Time 0, which translated to an average of 44.4 ( $SD = 21.9$ ) restricted care hours per week, at an average weekly cost of \$9,552.15. At Time 3, the mean NPDS score had reduced to 24.1 ( $SD = 18.1$ ), which represented a reduction in restricted weekly care hours of 7.8 hours ( $M = 36.6$  hours,  $SD = 23.0$  hours) and average cost of care of \$1,804.50 ( $M = \$7,747.65$ ,  $SD = \$4,655.81$ ). On average, clients became more independent, required less care, and had reduced care costs after three additional months in Brightwater rehabilitation. These mean trends are supported by changes in median estimates over the study period (Appendix 2: Additional Statistical Analyses).

**Table 9. Changes in Dependency Scores, Total Care Hours, and Average Cost (AUD) over the Study Period (n=14)**

NPCNA	Time 0		Time 3	
	Mean ( <i>SD</i> )	95% CI	Mean ( <i>SD</i> )	95% CI
Dependency	26.9 (18.7)	[16.1, 37.7]	24.1 (18.1)	[13.7, 34.6]
Care hours/week	44.4 (21.9)	[31.7, 57.0]	36.6 (23.0)	[23.3, 49.9]
Cost/week	\$9,552.15 (5,884.68)	[6,154.44, 12,949.86]	\$7,747.65 (4,655.81)	[5,059.47, 10,435.84]

**Notes.**

1.  $SD$  = standard deviation. CI = confidence interval.

Results of the repeated measures  $t$ -tests are given in Table 10. There was a small, statistically significant reduction in total weekly care hours over the study period. These results were confirmed by non-parametric Wilcoxon signed-rank tests (Appendix 2: Additional Statistical Analyses). Changes in dependency scores and weekly cost over the study period were not statistically significant.

**Table 10. Repeated Measures t-tests with NPCNA Outcomes as Dependent Variables and Time as the Independent Variable (n=14)**

NPCNA	Mean difference	t-test		
		t	p	Cohen's d
Dependency	2.8	0.74	0.472	0.15
Care hours/week	7.8	2.28	0.04	0.35
Cost/week	\$1,804.50	1.61	0.132	0.34

**Notes.**

1. Degrees of freedom = 13.  $p$  = probability value.
2. Cohen's  $d$  gives a standardised measure of effect size; effect size estimates were interpreted in accordance with Cohen's [113] guidelines for small ( $d = 0.2$ ), medium ( $d = 0.5$ ), and large ( $d = 0.8$ ).
3. Prior to analysis, skewness and kurtosis of the difference values were examined and deemed sufficiently normally distributed for parametric methods.

### 5.4.2 Cost of Consumable Products

*There was a statistically significant reduction in the average cost of consumable products, from an estimated \$26.01 per day at Time 0 to \$16.10 at Time 3.*

*These figures represent a reduction of \$9.91 per client per day and thus \$3,614.80 per year.*

#### ***Reduction in the cost of consumable products to support continence***

At Time 0, the average daily cost of consumable products was \$26.01 ( $SD = \$18.83$ ) per client, which represents an average yearly cost of \$9,493.39 ( $SD = \$6,874.67$ ) per client (see Table 11). At Time 3, the average daily cost of consumables reduced to \$16.10 per client ( $SD = \$19.08$ ), representing an average yearly cost of \$5,878.59 ( $SD = \$6,964.87$ ). These figures demonstrate a reduction of approximately \$9.91 per client per day and thus \$3,614.80 per year. The results of a repeated measures  $t$ -test demonstrated that this cost reduction was significant and had a medium effect size,  $t_{(13)} = 3.65$ ,  $p = 0.003$ , Cohen's  $d = 0.52^1$ .

Median cost estimates were also calculated to account for the small sample size and considerable variance in the data, as well as to facilitate comparisons with previous research conducted on the cost of consumable products in Australia (i.e., Morris et al. [26]). The median daily cost of consumable products was \$17.14 (IQR = 11.59, 36.47) per client at Time 0. Three months after implementation, the median daily cost of consumables reduced to \$8.11 (5.07, 22.42) per client. A

<sup>1</sup> Skew (1.5) and kurtosis (1.7) of the difference values between the two means were below the recommended upper limits of 2 and 9, respectively, indicating the data were suitable for analysis using a repeated measures  $t$ -test [114].

Wilcoxon signed-rank on the median test also demonstrated a significant difference ( $z = -3.23, p < 0.001$ ).

**Table 11. Mean and Median Daily Cost of Consumable Products at Time 0 and Time 3 (n=14)**

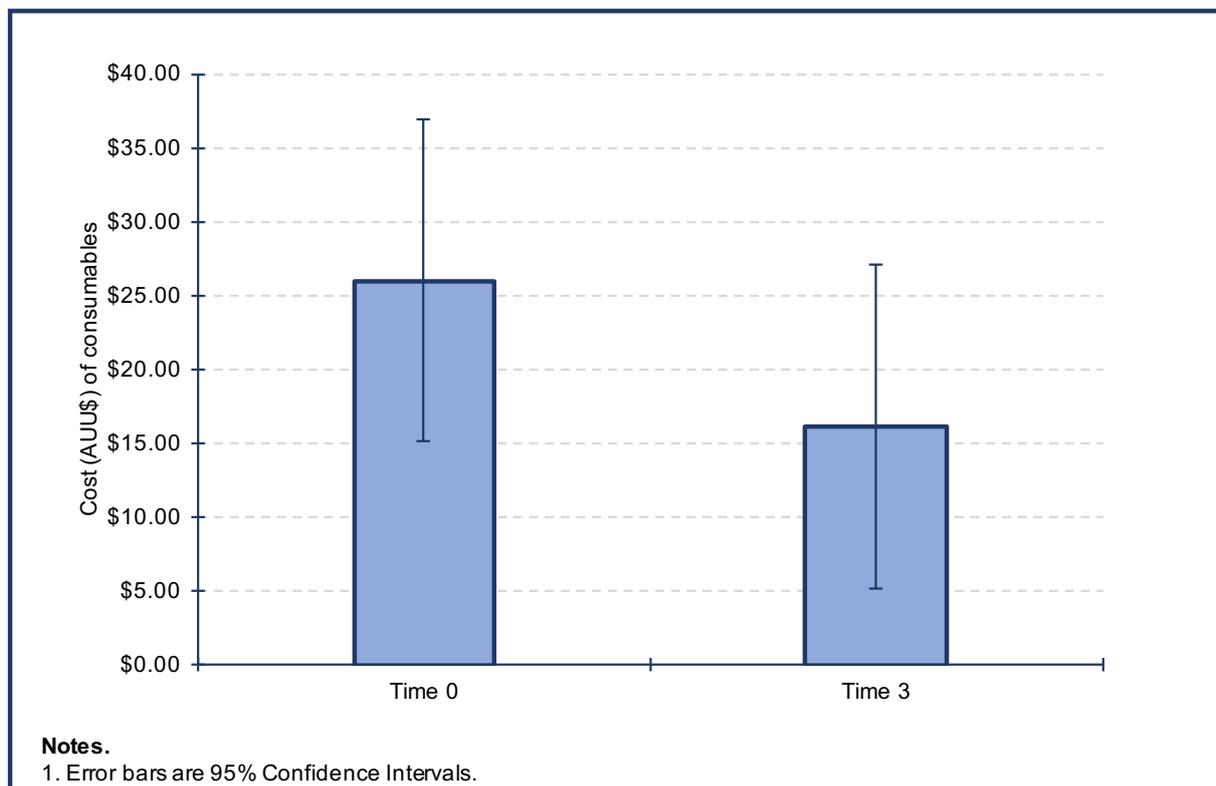
	Mean (SD)	95% CI	Median (IQR)
Time 0	\$26.01 (18.83)	[15.13, 36.88]	\$17.14 (11.59, 36.47)
Time 3	\$16.10 (19.08)	[5.09, 27.12]	\$8.11 (5.07, 22.42)

**Notes.**

1. SD = standard deviation. CI = confidence interval. IQR = interquartile range.

Figure 4 shows the average daily cost of consumables at Time 0 and Time 3.

**Figure 4. Average Daily Cost of Consumable Products at Time 0 and Time 3**



### 5.4.3 FIM+FAM: Independence in Activities of Daily Living

*There were statistically significant improvements in total FIM+FAM as well as motor and cognitive subscales. There was also significant item-level improvement in toileting, bladder (level of assistance), bowel (level of assistance), and bowel (frequency of accidents), indicating that clients' independence in toileting improved over the study.*

#### ***Increased independence in Total, Cognitive, and Motor domains***

Table 12 presents the median FIM+FAM total and subscale (cognitive, motor) scores, as well as item-level scores for toileting activities at Time 0 and Time 3 for the study population. Wilcoxon signed-rank tests demonstrated statistically significant increases in total FIM+FAM scores from Time 0 to Time 3 and across motor and cognitive subscales (Table 15). As expected, clients became more independent in both physical and cognitive activities of daily living over the study period.

#### ***Increased independence in toileting***

There were statistically significant improvements in four of five items assessing client independence in toileting: (1) toileting, (2) bladder (level of assistance), (3) bowel (level of assistance, frequency of accidents), and (4) bowel (frequency of accidents), indicating that client independence in toileting improved significantly over the study period. At baseline, all item-level median scores indicated complete dependence on assistance (i.e., the client completes less than half of the task). Three months after implementing ADs, median scores for toileting, bladder (level of assistance), and bowel (level of

assistance, frequency of accidents) indicated that clients performed more than half of the task themselves. Despite a numerical improvement in the bladder (frequency of accidents), this did not reach statistical significance.

**Table 12. Overall Changes in Median FIM+FAM Scores from Time 0 to Time 3 (n=14)**

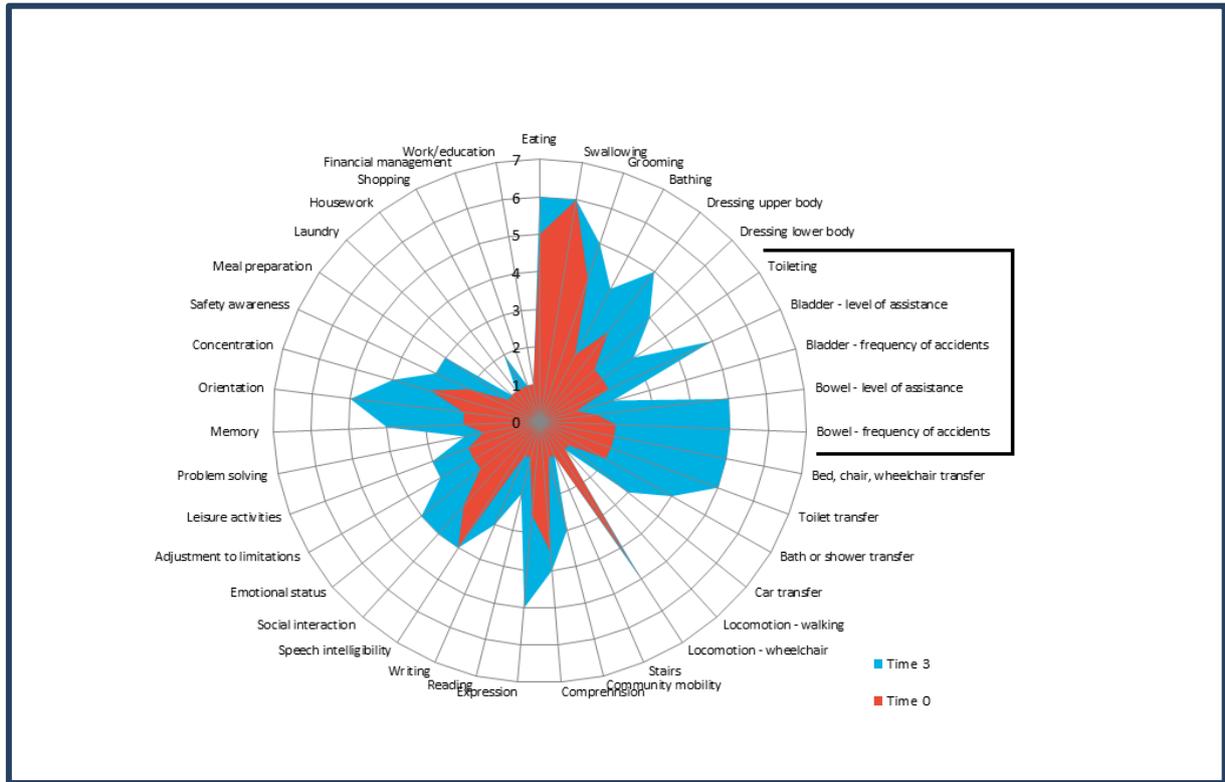
FIM+FAM	Median (IQR)		Wilcoxon signed-ranked test		
	Time 0	Time 3	Change	<i>z</i>	<i>p</i>
Motor	48.0 (31.8, 69.5)	73.0 (33.0, 84.8)	25.0	-2.61	0.009
Cognitive	35.0 (27.8, 59.3)	54 (35.8, 65.0)	19.0	-2.70	0.006
Total	91.5 (65.0, 122.0)	120.5 (86.5, 152.0)	29.0	-3.00	0.003
Item score					
Toileting	2.0 (1.0, 4.3)	3.5 (1.0, 6.0)	1.5	-2.41	0.016
Bladder (assistance)	3.0 (1.0, 5.3)	5.5 (2.0, 6.0)	2.5	-2.49	0.013
Bladder (frequency of accidents) <sup>a</sup>	1.0 (1.0, 6.5)	2.5 (2.0, 7.0)	1.5	-1.28	0.201
Bowel (assistance)	2.0 (1.0, 5.0)	5.0 (2.0, 6.3)	3.0	-2.56	0.011
Bowel (frequency of accidents) <sup>a</sup>	2.0 (1.0, 7.0)	6.0 (2.0, 7.0)	4.0	-2.40	0.017

**Notes.**

1. IQR = interquartile range. *p* = probability value.
2. Median Time 3 scores and change values based on clients for whom data were available at both time periods.
3. <sup>a</sup>Bladder and bowel (frequency of accidents) item scores not available for one client at Time 0.
4. Higher scores indicate increased independence.

Figure 5 presents a FIM+FAM radar chart with the overall item-level changes between the two time periods. The red area represents individual item scores at baseline, and the blue area illustrates the change in item scores over the study period. Item scores range from 0 (total assistance) at the inner circle to 7 (complete independence) at the outer circle. In addition to item-level gains in toileting and continence, gains were observed for items not directly related to continence/toileting, including eating, concentration, orientation, memory, problem-solving, and adjustment to limitations. However, many of these item-level gains are likely attributable to therapy input and rehabilitation progress as part of the client's time at Brightwater facilities.

Figure 5. Radar Chart Showing the Change in Median FIM+FAM Scores at the Item Level between Time 0 and Time 3



## FIM+FAM case examples

Three case examples were produced to illustrate changes in client independence and the need for assistance before and after implementing ADs.

### Client 6

**Client 6 was admitted with an indwelling catheter *in situ*. As part of the study intervention, the indwelling catheter was removed, and the level of physical assistance required to toilet decreased, including transfers and perineal hygiene. Client 6 now uses a wristwatch to prompt to toilet regularly (AD) to manage continence, as well as pads (consumable product). Client 6 FIM+FAM score changes:**

- Toileting subscale increased from a 2 (maximal assistance) at Time 0 to a 5 (supervision or set up only) at Time 3. Hands-on physical assistance is no longer required for toileting (supervision only).
- Bowel management – level of assistance subscale increased from a 1 (total assistance) at Time 0 to a 5 (supervision or setup assistance only) at Time 3.
- Bowel management – frequency of accidents subscale from a 1 (total assistance) at Time 0 to a 5 (supervision or setup assistance only) at Time 3.

### Client 11

**Client 11 was admitted with an indwelling catheter *in situ*. As part of intervention, Client 11 was transitioned to pads to manage continence needs. Pads were then ceased, and Client 11 now uses a non-spill bottle independently. Client 11 FIM+FAM score changes:**

- Toileting subscale increased from a 2 (maximal assistance) at Time 0 to a 6 (modified independence) at Time 3. Client 11 is now independent with toileting (perineal hygiene and clothing adjustments) but uses equipment (i.e., a rail when pulling up pants).
- Bladder management – level of assistance subscale increased from a 1 (total assistance) at Time 0 to a 6 (modified independence) at Time 3.
- Bladder management – frequency of accidents increased from a 1 (total assistance) to a 5 (supervision or setup assistance only) at Time 3.
- Bowel management – level of assistance subscale increased from a 1 (total assistance) to 6 (modified independence).
- Bowel management – frequency of accidents increased from a 1 (total assistance).

### Client 14

**Client 14 was admitted using pads to manage all continence needs. After intervention, Client 14 no longer required continence pads and managed toileting independently. Client 14 now uses a ping pong ball to assist with vision while standing to urinate only. Client 14 FIM+FAM score changes:**

- Toileting subscale increased from a 3 (moderate assistance) at Time 0 to a 6 (modified independence) at Time 3. Client 14 is now independent with toileting (perineal hygiene and clothing adjustments), but safety must be considered (due to client's reduced vision).
- Bladder management – level of assistance subscale increased from a 2 (maximal assistance) at Time 0 to a 6 (modified independence) at Time 3.
- Bladder management – frequency of accidents subscale increased from a 1 (total assistance) to having no accidents at Time 3.

### 5.4.4 QOLIBRI: Quality of Life

Of the 16 clients who were included in the study at baseline, five were determined not to have cognitive and communicative capacity to complete the QOLIBRI by their clinical treatment team. Of the 11 clients determined to have appropriate capacity, one was discharged from the service before completing the QOLIBRI at Time 3. Therefore, analyses of QOLIBRI data were conducted on a sub-group of ten clients.

#### *Quality of life after intervention*

*Contrary to expectations, the sample reported lower global and subscale QOLIBRI scores (and thus lower quality of life) after intervention. However, these changes were not significant.*

Table 13 presents the medians for QOLIBRI global scores and each of the six subscales for Time 0 and Time 3. Higher scores indicate better quality of life. The study population reported lower global and subscale QOLIBRI scores (and thus lower HRQOL) at Time 3 than at Time 0. The greatest decline was seen for feelings and physical problems subscales, suggesting that clients were more bothered by negative feelings (e.g., boredom, loneliness) and physical problems (e.g., slowness/clumsiness of movement, problems with seeing or hearing) at Time 3. However, all statistical comparisons between the two periods were non-significant (Table 13).

**Table 13. Overall Changes in Median QOLIBRI Scores from Baseline (Time 0) to Three Months after Implementing ADs (Time 3) (n=10)**

QOLIBRI	Median (IQR)		Wilcoxon signed-ranked test		
	Time 0	Time 3	Change	z	p
<b>Global score</b>	56.1 (47.3, 66.6)	51.0 (37.2, 65.7)	-5.1	1.23	0.221
<b>Subscale score</b>					
Cognition	69.6 (53.6, 81.3)	57.1 (48.2, 67.0)	-12.5	-1.72	0.086
Emotions	64.3 (40.2, 76.8)	62.5 (39.3, 68.8)	-1.8	-0.66	0.507
Independence	57.1 (49.1, 68.8)	51.8 (34.8, 61.6)	-5.3	-0.61	0.540
Social	66.7 (44.8, 75.0)	60.4 (27.1, 70.8)	-6.3	-1.3	0.206
Feelings	60.0 (20.0, 65.0)	45.0 (23.8, 62.5)	-15	-0.66	0.512
Physical	50.0 (28.5, 57.5)	35.0 (21.3, 56.3)	-15	-1.17	0.241

**Notes.**

1. IQR = interquartile range. p = probability value.

## 5.5 Intervention Outcomes by Brain Injury Diagnosis

Table 14 shows intervention outcomes stratified by brain injury diagnosis. In terms of NPCNA data, total weekly care hours required for toileting and continence reduced from Time 0 to Time 3 for all diagnostic groups. The cost of care declined for the traumatic and hypoxic brain injury groups, but not the stroke group.

All diagnostic groups showed a reduction in the cost of consumable items after intervention. Total and subscale FIM+FAM scores improved from baseline to three-month follow-up for the stroke and traumatic brain injury groups; the client with hypoxic brain injury showed improvement in motor but not cognitive or total scores. Global QOLIBRI scores declined for all diagnostic groups, with the least decline reported by those with traumatic brain injury.

### 5.5.1 Stroke

The stroke group showed a greater reduction in care hours than the traumatic brain injury group, but not the client with hypoxic brain injury. Average care hours reduced by more than four hours per week three months after intervention for the stroke group; however, this did not translate to a cost saving. Rather, a small cost increase (\$58.00) was observed. This increase was accounted for by an increase in the cost of care for two clients: client 5 and client 10. To demonstrate, when client 5 and client 10 were omitted from the analysis, stroke clients required a mean of 19.0 ( $SD = 4.5$ ) weekly care hours for continence and toileting at an average cost of \$7,762.25 ( $SD = \$5,375.94$ ) at Time 0. At Time 3, these figures reduced to an average of 11.6 weekly care hours, which cost \$6,707.00 ( $SD = \$4,663.99$ ). These figures represent a reduction in care hours of 7.4 and a cost reduction of \$1,055.25.

At Time 0, the average daily cost of consumables for the stroke group was \$29.63. This cost declined by \$11.61 after intervention to \$18.03.

The stroke group had the lowest FIM+FAM total scores (i.e., least independence) at Time 0. After intervention, the stroke group demonstrated the greatest gains in total function of all groups over the study period. Stroke clients improved in total and across motor and cognitive subscales. The group improved more in motor than cognitive domains of independence.

Of all diagnostic groups, clients with stroke reported the highest quality of life at Time 0 and Time 3, and across four of the six subscales. Still, this group demonstrated a decline in global QOLIBRI scores and five of six subscales. The greatest decline in quality of life for stroke clients was reported in satisfaction with cognitive abilities, emotions, and independence and daily life functions. Clients in the stroke group reported some improvement in satisfaction with social relationships.

### 5.5.2 Traumatic Brain Injury

Clients with traumatic brain injury had the lowest mean overall dependency in toileting and continence, average weekly care hours, and average cost per week of all diagnostic groups at Time 0 and Time 3. Weekly care hours reduced by more than one-hour post-intervention for clients with traumatic brain injury, which represented a reduction in the average weekly cost of \$1,324.00. However, these changes were strongly impacted by the data of one client with traumatic brain injury. Of the three clients with traumatic brain injury, two (client 9 and client 15) did not require staff intervention to toilet and did not have issues with urinary or faecal incontinence as determined by their dependency scores for toileting/continence items. Therefore, the cost of care was \$0.00 for both clients. For these two clients, continence and toileting issues were managed through the use of

consumable products and ADs. The third client (client 3) required an estimated 24.5 hours of weekly care for continence and toileting at an average cost of \$16,874.00 at Time 0. At Time 3, client 3 required 21.0 hours of weekly care at an average cost of \$12,992.00. This represents a reduction in weekly care of 3.5 hours and a cost saving of \$3,882.

The cost of consumables was lowest for clients with traumatic brain injury at both measurement points. At Time 0, the average daily cost of consumables was \$11.13. After intervention, the average daily cost of consumables declined to \$8.27, which represents a cost reduction of \$2.86.

Clients with traumatic brain injury improved in all scales of the FIM+FAM, with the greatest improvement observed in cognitive domains. Of all diagnostic groups, clients with traumatic brain injury demonstrated the greatest improvement in cognitive function and highest overall independence at both measurement points.

In terms of quality of life, the traumatic brain injury group reported the greatest negative change in the domains of feelings and physical problems; however, there was some client-reported improvement in the emotional view of oneself and independence/daily life functions.

### **5.5.3 Hypoxic Brain Injury**

The client with hypoxic brain injury had the highest overall dependency in toileting and continence, weekly care hours, and average cost per week at both measurement points. The greatest reduction in care hours and cost was observed for the client with brain injury from hypoxia. After intervention, required care hours for the client reduced by 10.5 hours, which translated to a cost reduction of \$10,500.00.

Of all diagnostic groups, the mean cost of consumables was highest for the client with hypoxic brain injury at both measurement points; however, this client also showed the greatest cost reduction after intervention. At Time 0, the average daily cost of consumables was \$34.41. This declined by \$14.00 to \$20.41.

In terms of independence, the client showed a slight improvement in motor (2.0 points) but not cognitive or total FIM+FAM scores.

The client with hypoxic brain injury reported the greatest reduction in global quality of life from Time 0 to Time 3 of all diagnostic groups, especially in satisfaction with social relationships and bother due to physical problems.

Table 14. Intervention Outcomes Stratified by Brain Injury Diagnosis

Outcome	Stroke (n=10)			Trauma (n=3) <sup>a</sup>			Hypoxia (n=1) <sup>b</sup>		
	Time 0	Time 3	Change	Time 0	Time 3	Change	Time 0	Time 3	Change
<b>NPICNA</b>									
NPDS score									
Bladder (assistance)	2.6 (1.7)	2.0 (1.3)	-0.6	1.3 (2.3)	1.3 (2.3)	0.0	4.0	4.0	0.0
Urinary incontinence	0.6 (1.0)	0.8 (0.8)	+0.2	1.0 (1.7)	0.7 (1.2)	-0.3	1.0	0.0	-1.0
Bowel (assistance)	2.7 (1.3)	2.5 (1.6)	-0.2	1.7 (2.9)	1.3 (2.3)	-0.4	5.0	4.0	-1.0
Faecal incontinence	0.6 (1.3)	0.5 (0.8)	-0.1	0.7 (1.2)	1.3 (1.2)	+0.6	0.0	0.0	0.0
Total	7.5 (3.4)	5.5 (4.2)	-2.0	4.7 (8.1)	4.7 (6.4)	0.0	10.0	8.0	-2.0
Care hours/week	16.1 (7.6)	11.55 (7.2)	-4.6	8.2 (14.2)	7.0 (12.1)	-1.2	28.0	17.50	-10.5
Cost/week	\$6,775.00 (5,346.49)	\$6,833.60 (\$4,121.02)	+\$58.60	\$5,624.67 (9,742.21)	\$4,300.67 (7,500.93)	-\$1,324.00	\$16,874.00	\$11,304.00	-\$5,570.00
<b>Consumables</b>	\$29.63 (\$20.26)	\$18.03 (\$22.02)	-\$11.60	\$11.13 (\$5.14)	\$8.27 (\$8.01)	-\$2.86	\$34.41	\$20.41	-\$14.00
<b>FIM+FAM</b>									
Motor	48.0 (38.5, 68.0)	73.0 (49.5, 83.3)	+25.0	69.0	84.0	+15.0	32.0	34.0	+2.0
Cognitive	35.0 (26.0, 59.5)	45.5 (34.3, 67.5)	+10.5	31.0	64.0	+33.0	60.0	58.0	-2.0
Total	84.5 (65.0, 122.0)	120.5 (84.5, 152.0)	+36.0	118	148	+30.0	92.0	92.0	0.0

Table 14. (Continued) Intervention Outcomes Stratified by Brain Injury Diagnosis

Outcome	Stroke (n=10)			Trauma (n=3) <sup>a</sup>			Hypoxia (n=1) <sup>b</sup>		
	Time 0	Time 3	Change	Time 0	Time 3	Change	Time 0	Time 3	Change
<b>QOLIBRI</b>									
Global score	64.5 (48.3, 70.8)	59.5 (39.7, 66.9)	-5.0	50.0	48.6	-1.4	41.2	29.7	-11.5
Cognition	75.0 (58.0, 90.2)	60.7 (48.2, 77.7)	-14.3	57.1	53.6	-3.5	64.3	50.0	-14.3
Emotions	73.2 (44.6, 83.9)	64.3 (50.0, 69.6)	-8.9	60.7	64.3	+3.6	32.1	17.9	-14.2
Independence	60.7 (39.3, 72.3)	51.8 (31.2, 66.1)	-8.9	53.6	57.1	+3.5	46.4	35.7	-10.7
Social	58.3 (39.6, 77.1)	64.6 (25.0, 72.9)	+6.3	66.7	62.5	-4.2	66.7	33.3	-33.4
Feelings	62.5 (47.5, 68.8)	57.5 (47.5, 71.3)	-5.0	40.0	20.0	-20.0	20.0	30.0	+10.0
Physical	55.0 (41.3, 68.8)	50.0 (28.8, 62.5)	-5.0	45.0	30.0	-15.0	24.0	5.0	-19.0

**Notes.**

1. Group sizes for QOLIBRI data: stroke (n=6), trauma (n=3), and hypoxia (n=1).
2. Mean scores (with standard deviations in parentheses) are presented for NPCNA and consumable cost data.
3. Median scores (with interquartile range in parentheses) are presented for FIM+FAM and QOLIBRI data.
4. <sup>a</sup>For clients with traumatic brain injury, interquartile ranges (FIM+FAM, QOLIBRI) are not computed due to small group size (n=3).
5. <sup>b</sup>For the client with hypoxic brain injury, measures of variance (standard deviation, interquartile range) are not computed as n=1; therefore, mean and median scores represent actual client scores.

## 5.6 Intervention Outcomes by Level of Dependency at Baseline

Table 15 shows intervention outcomes stratified by level of dependency at baseline. Total weekly care hours and average cost required for toileting and continence reduced from Time 0 to Time 3 for clients classified as medium and high dependency at baseline, but not clients classified as low dependency at baseline. The cost of consumables declined for all dependency groups. The FIM+FAM total and cognitive subscale scores improved for all dependency groups over the study period, indicating increased independence. The FIM+FAM motor scores improved for the medium- and high-dependency groups, but not the low-dependency group. In terms of QOLIBRI data, median global scores declined from Time 0 to Time 3 for clients classified as low and high dependency at baseline, suggesting a lower overall quality of life after intervention. Global scores for medium-dependency clients remained relatively constant, and by Time 3, this group reported slightly higher global quality of life than low- and high-dependency groups.

### 5.6.1 Low Dependency

Of all dependency groups, the two clients classified as low dependency at baseline had the lowest overall dependency in toileting and continence, average weekly care hours (0.0), and average cost per week (\$0.00) at Time 0. After intervention, however, the estimated average weekly care hours of the two clients (client 10, client 9) increased by 5.3 hours, which translated to an average weekly cost increase of \$3,670.00 per client. This increase was accounted for by an increase in the care required for one client (client 10). At Time 0, client 10 required 0 hours of continence/toileting care at \$0.0 cost. At Time 3, client 10 required 10.5 total care hours per week at an average weekly cost of \$7,340.00. Client 9's dependency scores for toileting/continence, required care hours, and cost remained stable (i.e., at 0) over the study period.

Low-dependency clients had the lowest daily cost of consumables at Time 0. By Time 3, the cost of consumables for this group was slightly higher than for the medium-dependency group. Still, the daily cost of consumables decreased for these clients, from \$12.25 at Time 0 to \$5.64 at Time 3. This represents a cost reduction of \$6.61.

At Time 0, the two clients had the highest total and motor scores (i.e., greater independence), but not cognitive scores. These clients made gains in cognitive and total scores but not motor domains of independence after intervention.

Low-dependency clients reported the highest global quality of life, and across five of the six subscales at Time 0. However, low-dependency clients reported the greatest decline in satisfaction with social relationships and greatest increase in bother due to physical problems over the study period.

### 5.6.2 Medium Dependency

The greatest reduction in average care hours and cost was observed for the five medium-dependency clients, with a reduction in estimated average care of 8.1 hours per week, which translated to a cost reduction of \$1,721.20. At Time 3, these clients had a lower overall dependency for toileting and continence, roughly the same weekly care hours, and smaller average weekly cost than clients classified as low dependency at baseline. This result is accounted for by changes in functional status over the study period: one client (client 3) classified as low dependency at Time 0

had poorer functional status (medium dependency) at Time 3, but two clients classified as medium dependency at Time 0 had improved functional status (low dependency) at Time 3.

The greatest reduction in the cost of consumables was observed for the medium-dependency group. At Time 0, the cost of consumables was \$17.07. This reduced by \$11.72 to \$5.35 at Time 3.

In terms of independence, medium-dependency clients had the highest FIM+FAM cognitive scores at Time 0. Of all dependency groups, those classified as medium dependency at baseline improved the most in total FIM+FAM scores from Time 0 to Time 3. By Time 3, medium-dependency clients had the highest motor, cognitive, and total scores, indicating the greatest level of independence. These clients showed greater gains in motor than cognitive domains.

Clients classified as medium dependency at baseline reported the lowest global QOLIBRI scores of all dependency groups at Time 0, indicating the worst quality of life. However, QOLIBRI global scores remained relatively stable for this group, and at Time 3 global scores were similar to but slightly higher (i.e., better quality of life) than the low- and high-dependency groups. Still, QOLIBRI reports for medium clients demonstrated declines in subscale scores, with the greatest decline reported due to bother about physical problems and negative feelings.

### 5.6.3 High Dependency

High-dependency clients (n=7) had the highest overall dependency scores, weekly care hours, and average cost per week at both measurement points. Still, these clients demonstrated improvements, and average care hours reduced by 4.3 hours from Time 0 to Time 3, translating to a cost reduction of \$1,085.69 per client per week.

These clients had the highest daily cost of consumables at Time 0 (\$36.33) and Time 3 (\$26.78). A cost reduction of \$9.55 was observed after intervention.

The high-dependency group had the lowest FIM+FAM total, cognitive, and motor scores at both measurement points (i.e., least independence). After intervention, little change was observed in motor subscores between Time 0 and Time 3, and there was greater improvement evident for cognitive domains.

High-dependency clients reported the lowest global QOLIBRI scores (i.e., lowest quality of life) of all groups at Time 3, and across three of the six subscales (cognition, independence, feelings). These clients reported the greatest decline in independence/daily life function and feelings at Time 3.

Table 15. Intervention Outcomes Stratified by Level of Dependency at Baseline

Outcome	Low Dependency (n=2) <sup>a</sup>			Medium Dependency (n=5)			High Dependency (n=7)		
	Time 0	Time 3	Change	Time 0	Time 3	Change	Time 0	Time 3	Change
<b>NPCNA</b>									
NPDS score									
Bladder (assistance)	0.0 (0.0)	1.0 (1.4)	+1.0	2.0 (1.2)	0.8 (1.1)	-1.2	3.4 (0.8)	3.1 (1.1)	-0.3
Urinary incontinence	0.5 (0.7)	0.5 (0.7)	0.0	0.4 (0.5)	0.2 (0.4)	-0.2	1.0 (1.2)	1.1 (0.9)	+1.0
Bowel (assistance)	0.0 (0.0)	1.0 (1.4)	+1.0	2.0 (1.2)	1.2 (1.6)	-0.8	3.9 (1.2)	3.6 (1.0)	-0.3
Faecal incontinence	0.0 (0.0)	2.0 (0.0)	+2.0	0.0 (0.0)	0.0 (0.0)	0.0	1.1 (1.5)	0.7 (1.0)	-0.4
Total	0.5 (0.7)	4.5 (3.5)	+4.0	4.4 (2.7)	2.2 (3.0)	-2.2	9.4 (4.0)	8.6 (2.8)	-0.8
Care hours/week	0.0 (0.0)	5.3 (7.4)	+5.3	13.7 (8.6)	5.6 (7.8)	-8.1	20.8 (6.6)	16.5 (4.7)	-4.3
Cost/week	\$0.0 (\$0.0)	\$3,670.00 (\$5,190.16)	\$3,670.0 0	\$4,657.20 (\$3,700.74)	\$2,936.00 (\$4,020.28)	\$4,654.26 -\$4,020.28	\$11,173.14 (\$6,437.27)	\$10,087.43 (\$2,660.77)	-\$1,085.71
<b>Consumables</b>	\$12.25 (\$4.91)	\$5.64 (\$4.00)	-\$6.61	\$17.07 (\$10.89)	\$5.35 (\$1.62)	-\$11.72	\$36.33 (\$20.78)	\$26.78 (\$22.78)	-\$9.55
<b>FIM+FAM</b>									
Motor	80.0	78.0	-2.0	67.0	87.0	+20.0	32.0	34.0	+2.0
	-	-		(50.0, 70.0)	(73.5, 88.5)		(28.0, 44.0)	(28.0, 74.0)	
Cognitive	43.0	62.5	+19.5	59.0	68.0	+9.0	28.0	36.0	+8.0
	-	-		(44.5, 76.5)	(52.5, 79.0)		(23.0, 34.0)	(32.0, 50.0)	
Total	123.0	140.5	+17.5	120	155.0	+35.0	65.0	92.0	+27.0
	-	-		(104.5, 139.5)	(131.0, 162.5)		(51.0, 78.0)	(62.0, 117.0)	

Table 15. (Continued) Intervention Outcomes Stratified by Level of Dependency at Baseline

Outcome	Low Dependency (n=2) <sup>a</sup>			Medium Dependency (n=5)			High Dependency (n=7)		
	Time 0	Time 3	Change	Time 0	Time 3	Change	Time 0	Time 3	Change
<b>QOLIBRI</b>									
Global score	65.5	50.0	-15.5	50.0	51.0	+1.0	56.8	47.3	-9.5
	-	-	-	(43.2, 68.4)	(41.6, 63.0)		(43.4, 65.0)	(32.3, 62.8)	
Cognition	57.1	51.8	-5.3	69.6	62.5	-7.1	76.8	51.8	-9.5
	-	-	-	(38.4, 76.8)	(55.4, 72.3)		(58.9, 92.0)	(36.6, 77.7)	
Emotions	71.4	66.1	-5.3	55.4	50.0	-5.4	57.1	60.7	+3.6
	-	-	-	(33.9, 76.8)	(39.3, 71.4)		(34.8, 84.8)	(26.8, 70.5)	
Independence	69.6	62.5	-7.1	50.0	53.6	+3.6	57.1	46.4	-25.0
	-	-	-	(17.9, 68.8)	(33.0, 63.4)		(48.2, 60.7)	(33.0, 57.1)	
Social	72.9	39.6	-33.3	56.3	60.4	+4.1	62.5	52.1	+3.6
	-	-	-	(36.5, 79.2)	(39.6, 68.7)		(45.8, 72.9)	(8.3, 77.1)	
Feelings	60.0	37.5	-22.5	62.5	52.5	-10.0	30.0	35.0	-10.7
	-	-	-	(30.0, 65.0)	(27.5, 58.8)		(12.5, 70.0)	(26.3, 62.5)	
Physical	60.0	32.5	-27.5	55.0	30.0	-25.0	37.5	42.5	-10.4
	-	-	-	(21.3, 73.8)	(26.3, 52.5)		(25.5, 45.0)	(13.8, 638)	

**Notes.**

1. Group sizes for QOLIBRI data: low dependency (n=2), medium dependency (n=4), and high dependency (n=4).
2. Mean scores (with standard deviations in parentheses) are presented for NPCNA and consumable cost data.
3. Median scores (with interquartile range in parentheses) are presented for FIM+FAM and QOLIBRI data.
4. <sup>a</sup>For low-dependency clients, interquartile ranges (FIM+FAM, QOLIBRI) are not computed due to small group size (n=2).

## 5.7 Client Satisfaction with ADs Survey

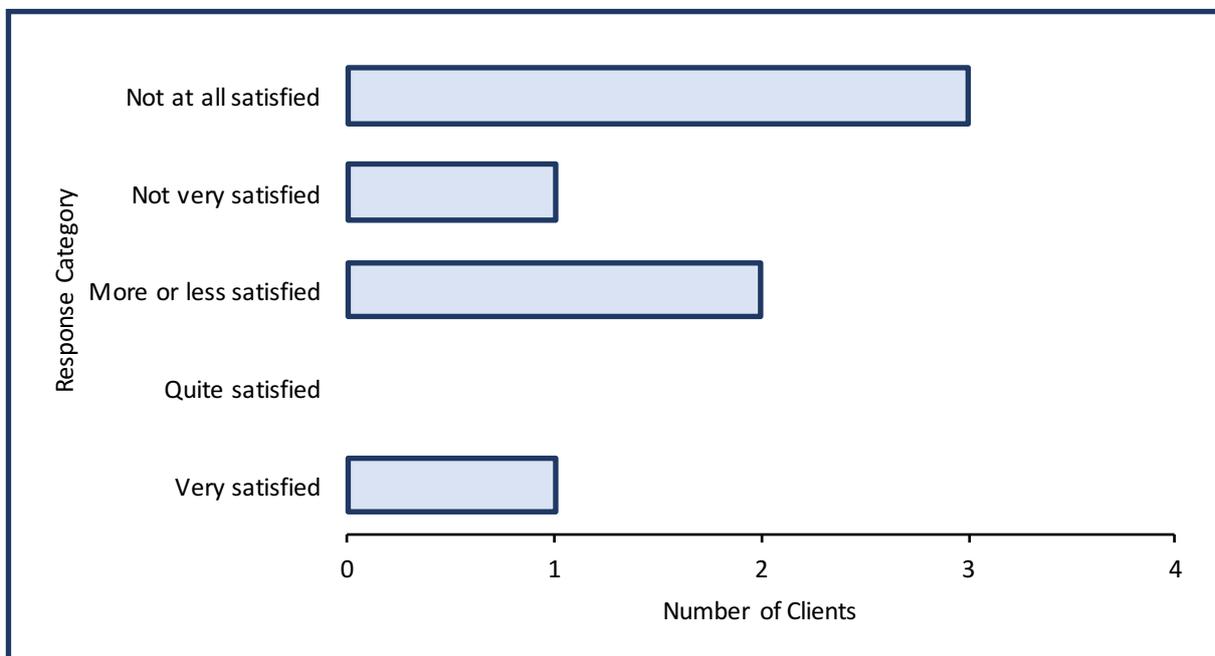
Of the 16 clients included in the project, nine were no longer receiving rehabilitation at a Brightwater site when the client satisfaction survey was administered. All of the seven clients still receiving rehabilitation at Oats Street or Marangaroo rehabilitation sites completed the survey.

Figure 6 shows client endorsement of each of the five satisfaction categories. Four clients reported that they were not very satisfied ( $n=1$ ) or not at all satisfied ( $n=3$ ) with their allocated device. Three clients reported that they were more or less satisfied ( $n=2$ ) or very satisfied ( $n=1$ ) with their allocated device.

Three of the seven clients who responded to the survey also provided written feedback. Of these, one reported that they were not at all satisfied with their device, one was not very satisfied, and one was more or less satisfied.

The client who reported that they were not at all satisfied with the device had been allocated a long-handled wiper following assessment but stated that "... it's of no use because I can reach the backside better than I used to" and that "I can't get it to reach the back area." The client who was not very satisfied with the device had been allocated a non-spill bottle; the client stated that they "prefer paper bottles," that the non-spill bottle was "surprisingly easy to overfill," and that it was "hard to empty without getting wet." The client who reported that they were more or less satisfied had been allocated a ping pong ball as a visual aid; the client stated that "it was helpful in a way... to see it."

Figure 6. Results of Client Satisfaction Survey





# 6

## Results: Current Staff and Organisational Practices

Six key findings regarding current practice in continence emerged from qualitative observation:

1. Insufficient emphasis on client-centred continence care.
2. Poor coordination of care.
3. Lack of standardised assessment protocols and procedure.
4. Limitations of clinical documentation.
5. Uncertainty about funding for continence products.
6. Demand for further staff education and training.

### 6.1 Qualitative Observation

#### *Insufficient emphasis on client-centred continence care*

Participating clients reported that they were rarely consulted by staff regarding their needs, preferences, and goals around continence prior to participating in the study. Further, an emphasis on the importance of consulting clients when providing continence care, especially regarding their needs, preferences, and experiences was absent from continence management policy and procedure.

#### *Poor coordination of continence care*

**Lack of role clarity.** The current policy provides an incomplete definition of continence management roles and responsibilities for disability support, allied health, and nursing staff. In particular, there is a lack of clear information regarding who is to complete care plans, individualised toileting routines, re-assessment and evaluations, and staff education around continence care.

**Over-reliance on a single continence champion.** Perhaps due to a lack of formalised procedure, continence management in practice is often the primary responsibility of a single nurse (with or without acknowledgement as the continence champion) and with no designated leave cover. In this role, the nurse was responsible for the allocation of continence aids and monitoring, adaptation of continence management plans, and staff education.

**Insufficient information regarding specialist consultation.** The existing continence procedure also states that staff can consult professionals trained in continence management to provide additional expertise; however, no information is given regarding whether specialists are internal or external, and no recommendations are made regarding whom to consult or how to consult.

### ***Lack of standardised continence assessment protocols and procedure***

Internal staff from different disciplines and external representatives have different assessment protocols and processes in place. Discussion with allied health staff across the participating Brightwater sites showed that physiotherapists primarily use Brightwater specific forms, but occupational therapists primarily use informal functional/observational assessment and a variety of formal cognitive assessments (depending on client capacity). No parameters were currently in place for the selection of assessment tools.

### ***Limitations of clinical documentation***

Some aspects of clinical documentation relevant to continence and toileting were incomplete or insufficiently detailed. In particular, online documentation included limited detail regarding continence assessment and management plans. Client progress notes did not include actual times for continence pad changes or the quantities of fluid input/output throughout the day. No bladder diary was in place, and the component of client care plans covering toileting and continence (i.e., “Toileting and Continence (Bladder & Bowel)”) was often not filled out. Further, no clear information was documented on a client’s current toileting regime or a client’s current continence products, including the size and brand.

### ***Uncertainty about funding for continence products***

Staff informed researchers that some clients are not currently on funding schemes for continence aids. This is especially true for clients who are not eligible for compensation from the Insurance Commission for an acute ABI. In this case, the cost of continence products is covered by the organisation or the client themselves during on-site rehabilitation.

### ***Demand for further staff education and training***

Nursing, allied health, and disability support staff consulted the research team regarding clients’ continence needs, including those of clients not included in the study. Brightwater site service managers also consulted the research team to gain further information and recommendations around education and training for specific site staff. Clinical staff reported wanting more training around continence management.

As a result of these interactions, it was decided that a brief staff survey would be designed to examine nursing, allied health, and disability support staff knowledge of and practice in continence management. This survey was used in the study and is reported below.

## 6.2 Staff Surveys

### 6.2.1 Occupational data

All staff members (n=47) directly involved in clinical care at Oats Street and Marangaroo received a request to complete a staff survey. Of these staff, 24 (51%) responded to the survey. Nine (36%) were in allied health, five (21%) were nursing staff, and 10 (42%) were disability support workers. A breakdown of individual occupations is provided in Table 16.

**Table 16. Staff Occupational Data**

Staff Category	n
<b>Allied Health Staff</b>	
Therapy Assistant	2
Occupational Therapist	2
Physiotherapist	1
Psychologist	1
Rehabilitation Coordinator	1
Social Worker	1
Speech pathologist	1
<b>Nursing Staff</b>	
Registered Nurse	4
Enrolled Nurse	1
Disability Support Worker	10

### 6.2.2 Staff knowledge and practice

#### *Allied health staff*

Allied health staff (n=9) had a sound understanding of continence; however, many staff were unclear as to what interventions or ADs each client had in place for continence/toileting management. Three allied health staff were unsure whether each client had an individualised continence management plan, with two reporting that they were unsure as to the content of a client continence assessment. Allied health staff recommended further staff education to improve the management of continence for clients at Brightwater.

#### *Nursing staff*

Nursing staff had differing opinions regarding what is most important during a continence assessment. Some nurses (n=2) reported that they were most concerned with client wellbeing, with one nurse reporting that a holistic approach is most important and another reporting that a client's dignity and independence is essential. Other nurses (n=2) were concerned about continence status, with one nurse reporting that regularity of bladder and bowels is most important and another reporting that it is most important to consider client diagnosis, age, and current use of continence aids.

More than half (n=3) of nursing staff reported that they were not currently using the Brightwater specific continence assessment and that they were unsure whether this assessment was adequate to determine client continence and toileting needs. All nurses reported that continence assessment included bladder and bowel assessment and that they assessed skin integrity regularly. Two nurses reported that they regularly checked for urinary tract infections, but none reported that they assessed pelvic floor function. Four of five nurses reported that a continence management plan was not currently in place for each client.

All nurses reported that the site's continence nurse is responsible for deciding on the type of consumables and ADs that are allocated to each client. Respondents also provided information regarding what kinds of consumable products and ADs they used. All reported that pads were used, and some reported that pull-ups (n=2), bottles (n=2), urodomes (n=2), alarms (n=1), and aperients (n=1) were used.

### ***Disability support workers***

Most (n=7) disability support workers knew what type of consumable products and ADs each client had been allocated in their house, as well as what fluids each client was drinking in their house (n=8). However, less than half (n=4) knew the quantity of fluid their clients drank each day, and only five knew what their clients ate for breakfast and lunch. This may, however, be attributable to shift work, resulting in staff not necessarily being present at all times for a client. Half (n=5) of the disability support staff were unsure what information should be included in a continence assessment.

## **6.2.3 Staff Collaboration**

### ***Allied health staff***

Most (n=7) allied health staff members reported that nurses consulted them for input regarding client continence assessment, but fewer respondents (n=6) reported that client continence needs were consistently discussed during clinical team meetings. Allied health staff recommended appropriate documentation site-wide and further discussion regarding continence and toileting during team meetings to facilitate multidisciplinary collaboration.

### ***Nursing staff***

Only two nurses reported that they consulted allied health staff for input, which is inconsistent with reports from members of the allied health team. More than half of the nursing staff reported that they were unsure as to whether involving allied health staff is beneficial during continence assessment.

### ***Disability support workers***

Only 6 of 10 support workers reported that client toileting regimes are discussed at handover. The same number reported that they were consulted by nursing staff during continence assessments.

## 7

# Summary and Discussion

## 7.1 Summary

This project used a sample of 16 clients receiving staged, community-based brain injury rehabilitation at Brightwater Care Group (WA) to examine the impact of intervention with ADs for toileting and continence on care needs and cost of care, cost of consumable products, independence, and quality of life in people with an ABI. The results of the study indicated a number of positive outcomes from intervention. However, several limitations to practice in continence management were also identified.

### ***Reduction in care needs and cost***

Care needs and costs reduced after intervention. Namely, estimated average care hours for toileting and continence reduced by 4.3 hours per client per week between Time 0 and Time 3, which represented a reduction in the average weekly cost of AUD633.29. This translates to a reduction in the average yearly cost of care of AUD32,931.60 per client.

### ***Reduction in the cost of consumable products***

There was a significant reduction in the average cost of consumable products over the study period, with an estimated reduction of \$9.91 per client per day and thus an estimated \$3,614.80 per client per year.

### ***Increased client independence***

Clients became more independent, with statistically significant improvements in total FIM+FAM as well as motor and cognitive subscales three months after intervention. There were also significant item-level improvements in toileting, bladder (level of assistance), bowel (level of assistance), and bowel (frequency of accidents), indicating an improvement in client independence in toileting over the study period.

### *Topics Covered in Summary & Discussion:*

- *Summary of study findings*
- *Discussion of client outcomes*
- *Discussion of current practice in continence management*
- *Study limitations*

### *Key Intervention Findings*

*The key findings of this study were that comprehensive assessments, tailored management plans, and assistive devices:*

- *Reduced care hours required for toileting by an estimated 4.3 hours per client per week, which represents an average reduction in care costs of AUD633.29 per client per week.*
- *Reduced average daily cost of consumable products by AUD9.91 per client.*
- *Improved client independence, with significant improvements in total as well as cognitive and motor subscales on a validated measure of independence (the FIM+FAM tool).*

### **Quality of life**

Despite improvements in independence, client-reported quality of life declined after intervention; however, no statistically significant changes were observed.

### **Gains by brain injury diagnosis**

Analysis of intervention outcomes by brain injury diagnosis (stroke, traumatic brain injury, hypoxic brain injury) demonstrated increased individual independence, a reduction in care hours, and lower cost of consumable products for all diagnostic groups. Cost of care reduced for clients with traumatic and hypoxic brain injury, but not clients with ABI following stroke. Quality of life declined for all diagnostic groups, with the least decline reported by those with traumatic brain injury.

### **Gains by level of dependency at baseline**

All dependency groups (low, medium, and high) demonstrated gains after intervention, including a reduction in the cost of consumable products and increased independence. Care hours and cost of care required for continence and toileting declined for medium- and high-dependency clients, but not low-dependency clients. Quality of life declined for low- and high-dependency clients but was stable for medium-dependency clients.

### **Client satisfaction with ADs**

There was variability in client reports of satisfaction with ADs allocated through intervention. Some clients (n=4)

reported that they were not satisfied with their AD, but others (n=3) reported that they were satisfied.

### **Practice in continence management**

Current practice in continence management was consistent with previous research in the sector, and seven key findings were identified from qualitative observation and staff surveys:

1. Insufficient emphasis on client-centred care.
2. Poor coordination of continence care.
3. Lack of standardised continence assessment protocols and procedure.
4. Limitations of clinical documentation.
5. Uncertainty about funding for continence products.
6. Need for further staff education and training.
7. Lack of staff collaboration.

## 7.2 Managing Continence in the ABI Population with Assistive Devices

### 7.2.1 Care Needs and Cost of Care

Incontinence greatly increases the cost of care [26]. To minimise the impact on the healthcare budget, it is essential to identify cost-effective ways to manage continence-related problems in people with an ABI.

#### Key findings for care needs and cost of care

- Prior to intervention, clients required an average of **15.3 hours** of care per week at a cost of **\$7,249.86**.
- Three months after intervention, clients required an average of **11.0 hours** of care, costing **\$6,616.57**.
- This represents a reduction in average care hours required for continence and toileting of approximately **4.3 hours** per client per week three months after intervention, which translates to a cost reduction of approximately **\$633.29** per client per week or **\$33,000** per year.

The project provides suggestive evidence that thorough continence assessment and management tailored to the individual's specific presenting problems confers not only a reduction in care hours but also a significant cost benefit. However, many people with continence problems experience symptomatic improvement over time [7, 13]. Further, therapy inputs during brain injury rehabilitation improve cognitive and mobility deficits that contribute to episodes of functional incontinence. Therefore, stronger evidence for the role of intervention would be derived using randomised controlled trials. Nevertheless, these data make an important contribution to our understanding of the cost benefits of effective continence management.

A large amount of staff time is dedicated to providing toileting assistance and managing continence. The estimate of average weekly care hours required for toileting and continence (15.3 hours) prior to intervention is similar to estimates from previous research in the sector. Morris and colleagues [26] found that patients receiving sub-acute neurologic rehabilitation required about two hours of care per day or 13.1 hours of care per week, which translated to an estimated daily cost of AUD50. By contrast, NPCNA data from this study produced a daily cost estimate of AUD1,035.70, which is 20 times greater than that produced by Morris and colleagues.

This substantial difference demonstrates the sizeable cost of care in the community context. Community care is especially time-consuming, as nursing and care staff typically provide care to one person at a time and need to travel between clients, often several times each day. Brightwater provides community-based rehabilitation *within a facility*, which involves much shorter, more frequent interactions with clients. Therefore, the cost estimates produced using the NPCNA algorithm are likely to be significantly higher than actual Brightwater care costs. Indeed, there is considerable research that inpatient rehabilitation, such as that provided at Brightwater, is more cost-efficient than community care [96, 115].

This project adapted the NPCNA instrument to be relevant to WA health and disability contexts and is now validated for the WA context, which can benefit future work. In the face of growing pressure on

healthcare budgets, it is necessary to provide evidence of cost-effectiveness. The NPCNA tool was designed to give a simple and quick estimate of care needs and cost and intended for routine use in busy clinical settings. The tool cannot replace full health economic analysis or actual flow of cash on a case-by-case basis, but it may still be a useful addition to assess the outcome of rehabilitation. In practice, the care timetable generated by the NPCNA can be used on an individual basis for discharge planning and in the preparation and funding of care plans in the community.

Despite the observed reduction in care hours and cost, these changes were not statistically significant. However, the study's limited sample size and considerable within-group variance may have inflated the Type II error rate (i.e., the probability of failing to reject a false null hypothesis). A sample of 55 participants would be required to have an 80% chance of detecting a significant change in care hours and cost over the study period (with an observed small- to medium-sized effect). Therefore, further research should use the above power calculations as a guide for the required participant numbers.

### 7.2.2 Consumable Products

Studies typically indicate that the majority of direct costs of incontinence are attributable to routine care, including the cost of consumable products such as continence pads and protection [23, 25]. The project estimated the cost of consumable products before and after intervention and found that clients required fewer consumable products for continence at a lower cost after intervention.

#### Key findings for consumable products

- Before intervention, the average daily cost of consumable products was **\$26.01** (median: \$17.14) per client. After intervention, the average daily cost of consumable products was **\$16.10** (median: \$8.11) per client.
- This represents a cost reduction in average cost of consumables of **\$9.91** per client per day or \$3,614.80 per year.

The estimated cost of consumables prior to intervention is similar to estimates from previous studies. In a 2005 Australian study by Morris and colleagues [26], the researchers found that the median daily cost of consumables amounted to about AUD11.60 after implementing standardised assessment and management programmes. Accounting for yearly inflation, this translates to an estimated AUD15.84 in 2018. In contrast, the median daily cost of consumables after intervention (at Time 3) was AUD8.11 per client, which is considerably lower than the estimate produced by Morris and colleagues. Given these comparisons, the results of the current project suggest that conducting and implementing continence assessment and management plans have the potential to reduce the cost of consumable products; however, the use of ADs appears may play a more substantial role in reducing the cost of consumable products.

### 7.2.3 Independence in Activities of Daily Living

Incontinence following an ABI has been associated with loss of functional independence, even after controlling for other prognostic factors [4, 7, 32, 33, 47–53]. Problems with continence may also interfere with an individual's ability to participate in rehabilitation programs by impacting quality of life, motivation, concentration, sleep, and other activities of daily living [41, 58, 59]. Therefore, incontinence should be considered not only as an indicator of brain injury severity and other medical complications but also as an important target for intervention.

The project findings suggest that appropriate and effective continence management is significant in supporting people with an ABI to increase their independence.

#### Three months after implementation of ADs for continence and toileting

- Clients required significantly less assistance to empty bladder and bowels and had significantly fewer episodes of faecal incontinence.
- Clients also became significantly more independent in cognitive and motor domains.

The ultimate goal of rehabilitation services for ABI is to maximise independence and reintegration to the community. The project results suggest that intervention with comprehensive continence assessment, tailored management, and ADs is effective in supporting people with an ABI to not only increase their independence in continence and toileting activities but also to achieve broader rehabilitation goals. Without a relevant comparison group, however, the extent to which other therapy inputs received as part of rehabilitation at Brightwater contributed to these gains is unclear. Therefore, to provide strong evidence for this suggestion would require an experimental study that includes a comparison group.

The findings also add to the growing literature on the usefulness of ADs in supporting people with an ABI to complete a broad range of activities of daily living, including cooking [79], budgeting [82], and social and functional communication [83, 84]. Together, these findings indicate that ADs are effective tools to support people with an ABI to live more independently.

### 7.2.4 Quality of Life

ABI profoundly impacts quality of life, and this population reports a lower quality of life compared to pre-injury levels and comparison groups [109, 116]. Rehabilitation services for brain injury are increasingly adopting holistic models of rehabilitation; therefore, the impact of intervention and rehabilitation on quality of life is an important consideration.

#### Despite increased client independence

- Clients reported lower global quality of life three months after intervention than at baseline, and across all six subscales.
- The decline in quality of life was greatest for feelings and physical problems, indicating that clients were more bothered by experiences such as loneliness, boredom, anxiety, pain, and slowness/clumsiness of movement.

The finding that clients were most bothered by physical problems (overall and in terms of change over the study period) is consistent with previous research in the stroke population. Studies have identified urinary incontinence as an important predictor of worse subjective experience of physical health (e.g., bodily pain, general health, physical functioning), even up to three years after injury [33]. The current

project adds to findings such as these by also including participants with ABI from trauma and hypoxia. In doing so, it revealed that emotional domains of life quality declined to a similar degree. This decline was primarily accounted for by an increase in negative feelings among clients with traumatic brain injury, which is commonly comorbid with mental health disorders such as depression and anxiety [117, 118].

Although the decline in quality of life did not reach statistical significance, the trends still warrant discussion given the low statistical power of the study. There is some evidence that quality of life decreases over time in the initial period after acquiring a brain injury, particularly as the individual begins to come to terms with the consequences of injury and as they attempt to reintegrate to the community [119]. Most clients in the study were injured less than two years prior; nine of the 16 participants participated in the project during the first year after injury and four participated in the second year after their injury. Of the remaining three clients, two had been injured less than four years prior. Therefore, it is feasible that clients' quality of life declined as their awareness of their impairments increased.

The overall decline in quality of life could be impacted by several additional factors, including:

- longer length of stay in rehabilitation
- decline in actual health status over the study period (some clients had hospital admissions between Time 0 and Time 3)
- increased concern about own health status due to the project focus
- social factors
- change in mental health status
- increased contact with the research team, who were both unfamiliar and asked questions of a personal nature
- less frequent interactions with staff, which could produce increased feelings of boredom or loneliness
- other extraneous factors.

That there are many possible causes of this decline underscores the need for research studies to examine this question. The underlying causes of this decline in quality of life need to be identified in order to plan appropriate and effective services and deliver high-quality care.

## 7.2.5 Brain Injury Diagnosis

### Key Findings by Brain Injury Diagnosis

- **Clients in all three diagnostic groups demonstrated gains after intervention.**
- The **stroke group** showed a reduction in care needs and cost of consumable products, but a small increase (\$58.00) in cost of continence care. This was as a result of two clients requiring increased medical intervention due to medical complications, which impacted their ability to toilet independently. The group became more independent in total, and motor and cognitive domains. Stroke clients reported a decline in global quality of life, with the greatest decline reported for satisfaction with cognitive abilities and independence.
- The three clients with **traumatic brain injury** had reduced care needs, cost of care, and cost of consumable products after intervention. Total independence improved, with greater improvement in cognitive than motor function. In terms of quality of life, clients reported the greatest negative change in the domains of feelings and physical problems.
- The client with **hypoxic brain injury** demonstrated the greatest reduction in care needs, cost of care, and cost of consumable products of all dependency groups after intervention. The client became more independent in motor but not cognitive domains of independence. The client reported the greatest reduction in quality of life, particularly due to reduced satisfaction with social relationships and bother due to physical problems.

The findings provide suggestive evidence that comprehensive assessment and tailored management, including ADs, can positively impact functional outcomes and cost for people with an ABI, irrespective of brain injury diagnosis.

The report also gives some indication that clients with different brain injury diagnoses face unique challenges to quality of life following brain injury. All clients reported a decline in quality of life after an additional three months in community rehabilitation, but clients with stroke reported the greatest negative change in satisfaction with cognitive abilities, traumatic brain injury clients reported the greatest negative change in the domains of feelings, and the client with hypoxia reported the greatest decline in satisfaction with social relationships. Brain injury rehabilitation services are increasingly focused on the holistic impact of rehabilitation and thus quality of life outcomes. To cater to the unique needs of clients with ABI, it is essential to understand potential vulnerabilities and to plan and deliver services accordingly.

The small number of clients and considerable variance in outcomes within each diagnostic group, however, make it difficult to characterise the actual impact of intervention on each sub-population. For example, although a decrease in care needs and cost of care was observed for clients with traumatic brain injury, two of the three clients were independent in toileting before intervention and primarily required assistance through the use of ADs. Therefore, the estimates should not be taken as generalisable. Research studies using larger client groups would help to establish more accurate and generalisable estimates regarding the intervention impact.

## 7.2.6 Level of Dependency

### Key Findings by Level of Dependency at Baseline

- **Clients in all three dependency groups demonstrated gains after intervention, including functional improvement, care needs, and costs over the study period.**
- Of all dependency groups, clients classified as **medium dependency** at baseline **showed the greatest overall gains** from intervention.
- The two **low-dependency clients** showed an increase in care needs and cost of care due to a decline in the health status of one client. The cost of consumables decreased. The clients made gains in cognitive and total independence, but not motor independence. These clients reported the greatest decline in quality of life of all diagnostic groups, especially due to an increase in bother due to physical problems.
- The five **medium-dependency clients** demonstrated the greatest reduction in care needs, cost of care, and cost of consumable products of all dependency groups. These clients also showed the greatest improvement in independence and reported a relatively stable global quality of life.
- The **stroke group** showed a reduction in care needs and cost of consumable products, but there was a small increase (\$58.00) in cost of continence care. Stroke clients became more independent in total, and motor and cognitive domains. The group reported a decline in global quality of life, with the greatest decline reported for satisfaction with cognitive abilities and independence.

This project demonstrated gains for clients in all three dependency groups after intervention with ADs, including functional improvement, reduction in care needs, and lower costs. Therefore, clients requiring all levels of care are likely to be positively impacted by interventions of this kind.

Compared to other dependency groups, however, medium-dependency clients required the least amount of care at the lowest cost after intervention, and this corresponded to an increase in functional independence and a negligible increase in quality of life. It is therefore reasonable to consider that interventions with ADs will have the greatest impact on medium-dependency clients. However, ABI is a *complex* and *dynamic* disease process, and although many clients improved over the study period, several clients also experienced a worsening of condition, with some requiring hospital admissions. Therefore, further research would be required to confirm this potential focus.

## 7.2.7 Satisfaction with Assistive Devices

Client satisfaction with ADs implemented during intervention varied. Although some clients reported that they were generally satisfied with their device, others indicated that they were not very or not at all satisfied. One client voiced that the device was no longer useful given the improvement in their mobility, and another client reported difficulties with use. The varying levels of client satisfaction underscore the importance of a client-centred approach that involves regularly consulting clients to understand their potentially changing continence needs and preferences. Following brain injury, many clients receiving specialist brain injury rehabilitation make significant functional gains, particularly in cognitive and motor capacity [120]. Given this considerable capacity for change in condition and thus continence status, it is critically important that continence management plans and ADs are regularly

evaluated to ensure that they are in line with the clients' changing needs and preferences as they progress in their rehabilitation.

## 7.3 Practice in Continence Management

The act of going to the toilet involves not only bladder and bowel actions, but also getting to and from the toilet, transferring onto and off the toilet, maintaining perineal hygiene, adjusting clothing, and practising adequate hand hygiene. The diverse sequelae of brain injury mean that consultation with all appropriate staff members involved in client care is critical to the management of continence-related difficulties in this vulnerable population. To meet a client's continence needs, preferences, and rehabilitation goals, it is critical that clients and their families are also involved in care decisions. To ensure that management is effective and efficient, strategies must be evidence-based.

### Seven key findings emerged from qualitative observation and staff surveys

1. Insufficient emphasis on client-centred continence care.
2. Poor coordination of continence care.
3. Lack of standardised continence assessment protocols and procedure.
4. Limitations of clinical documentation.
5. Uncertainty about funding for continence products.
6. Need for further staff education and training.
7. Lack of staff collaboration.

### 7.3.1 Insufficient Emphasis on Client-Centred Continence Care

Client-centred care is about viewing the person as an individual and expert in their own experience and incorporating the needs, values, and preferences of the person and their family into care decisions to optimise the person's experiences with care [121].

Collaboration between clients and staff in continence was lacking. Participating clients reported that they were rarely consulted by staff regarding their needs, preferences, and goals for continence management prior to participating in the study. Previous qualitative research conducted on stroke survivors receiving acute care has demonstrated similar results. Survivors have described a lack of communication with clinical staff about continence issues and few opportunities to engage in discussion about continence or plans for their continence care [122]. This current project suggests that collaboration between staff and clients in community rehabilitation contexts can also be improved.

The importance of client-centred practice should be formalised in organisational policy. Additional evidence-based strategies to support client-centred practice include discussion of client care plans and early, open communication with clients and their families [123], increased direct one-on-one care time with the client and their family [124], and using pictures, videos and/or storyboards for information exchange with patients and family members to improve patient preparedness and consistency of patient care [125].

### 7.3.2 Poor Coordination of Continence Care

**Lack of role clarity.** At the organisational level, current continence management policy and procedure do not provide a clear framework for individual staff contributions to all responsibilities in continence

management. In particular, the existing continence policy provides insufficient clarity of roles for clinical, allied health, and disability support staff in continence management under a model of collaborative practice.

Collaborative practice can improve resource efficiency and quality of care by improving the efficiency of multidisciplinary teams and reducing demands on staff [126–128]. However, sufficient role clarity is essential to achieve potential benefits [129]. A lack of role clarity can lead to underutilisation of professional expertise [129], which can compromise client outcomes and contribute to the inefficient use of resources [125]. Clear job descriptions can support staff to work to their full scope of practice [124, 130]. Additional strategies include ongoing professional development that addresses role optimisation and clarity [130–132] and facilitating a culture between professionals and other staff involved in care.

Therefore, the existing policy should be augmented to include guidance for different levels of staff around *all* responsibilities involved in continence management. In particular, information regarding who completes client care plans, individualised toileting routines, re-assessment and evaluation of care plans, and staff education in continence care must be embedded in organisational policy. Consideration should also be given to implementing other initiatives designed to address role optimisation and clarity.

**Over-reliance on a single continence champion.** Some teams primarily rely on one staff member (i.e., the continence champion) to provide the majority of continence management, including allocation of continence aids, monitoring and adapting continence management plans, and staff education. While the role of a continence champion may help to streamline continence requests, clinical practice guidelines recommend a multidisciplinary approach to continence management (e.g., *NSF guidelines*, 2017 [61]). A multidisciplinary approach may facilitate the delivery of a better care response and help to effectively manage the diversity of influences on continence status in people with an ABI (e.g., communicative and cognitive deficits, mobility, dietary intake).

**Insufficient information regarding specialist consultation.** Current procedure suggests that staff consult a continence management specialist during assessment; however, no information is given regarding whom to consult, under what circumstances, and how to do so, or whether specialists are internal or external. Consultation with a continence specialist is one of the few recommendations with a sound evidence base [69]. It is therefore essential that clients have access to specialist advice. The absence of clear guidance regarding specialist consultation has the potential to create staff uncertainty during care delivery, be an inefficient use of staff time and resources, and make consultation with a specialist less likely to occur. Staff should have access to clear procedural guidance for specialist consultation.

### 7.3.3 Lack of Standardised Assessment Protocols and Procedures

Currently, there are no parameters in place to guide the decisions of internal staff when selecting assessment tools. This can undermine continuity and consistency in decision-making, assessment, and care, in addition to compromising communication systems in the multidisciplinary team [133]. To maximise the quality of care, the multidisciplinary team should adopt a shared language of assessment by implementing parameters for the use of different assessment tools and methods.

### 7.3.4 Limitations of Clinical Documentation

Aspects of clinical documentation relevant to continence were often absent, insufficiently detailed, or out-of-date. A significant amount of information appears to be shared verbally, during daily handover, and at other times. These findings are not unique to the organisation or indeed rehabilitation services for brain injury, with many healthcare services reporting suboptimal documentation of client and patient information, as well as an over-reliance on verbal information sharing (e.g., [134–136]).

Quality documentation is essential for good clinical communication and continuity of care. Appropriate and up-to-date documentation ensures that assessment, changes in conditions, care provided, and important client information are documented to support the multidisciplinary team and external agency staff members to deliver care [137]. In contrast, poor documentation can lead to duplication, missing information, and delays [138], which have been linked to inferior quality of care and increased health care costs [134, 139–141]. Clinical documentation of client progress is also critical to assess the effectiveness of current intervention or management programmes and adapt them accordingly. It is therefore essential that efforts to improve clinical documentation are made. Evidence-based strategies to improve written documentation have been provided by Hepp and colleagues (2014) [138].

### 7.3.5 Uncertainty about Funding for Continence Products

Some Brightwater clients—who were not receiving funding from the Insurance Commission—are not currently on a continence product funding scheme. Consequently, there is uncertainty about how financial assistance will be provided for the purchase of products on discharge to the home. It is important that accessing funding is prioritised, both during on-site rehabilitation and at discharge. Although Brightwater staff report an increase in support from Brightwater sites to assist clients and their families in arranging the provision of continence aids and provide education into the National Continence Aids Payment Scheme, this process should be formalised. To do so, internal procedure should be implemented for client referrals to Silver Chain’s Continence Management and Advisory Service, which assesses the eligibility for the National Continence Aids Payment Scheme and state-funded schemes.

### 7.3.6 Need for Further Staff Education and Training

There is a demand for greater continence education and training from staff and site service managers. Researchers were consulted by all levels of staff involved in continence management regarding client continence needs, and site service managers consulted the research team to gain education and training for staff. Results of staff surveys confirmed not only a demand for increased education and training but also a need.

Previous research has reported a lack of continence education and training for clinical and support staff, and a staff focus on “containment” rather than rehabilitation based on individualised assessment and management [60, 122]. Educational interventions targeting staff have demonstrated positive impacts on staff knowledge and practice (e.g., Brady et al., 2015 [122]). Therefore, consideration should be given to providing all levels of staff with relevant education and training in client-centred continence care.

### 7.3.7 Lack of Staff Collaboration

Good formal and informal communication are critical to client-centred, collaborative care [130]. However, allied health, nursing, and disability support staff reported that client continence needs are

rarely discussed during team meetings or at handover. Staff meetings can facilitate collaborative communication [130]. To promote collaboration in the area of continence, staff meetings should timetable discussion of client continence status, needs, and preferences. Open communication is also important in reviewing and adapting continence management plans as required, and feedback on status is significant in ensuring client needs are met. Additionally, few nurses reported that they consulted other health professionals for input, with some questioning whether this would be beneficial for clients. This has the potential to undermine the quality of care through undermining a multidisciplinary approach and an underutilisation of professional expertise [129].

## 7.4 Study Limitations

This study has several limitations. First, the use of a single group design in which study participants served as their controls requires caution when attributing effects to the study intervention. It is always possible that other factors produced the observed outcomes, and there is good evidence that continence and functional outcomes improve with rehabilitation (e.g., Patel et al., 2001 [7]). Therefore, future evaluation using a more rigorous scientific design is needed to judge the impact of this intervention more precisely.

Second, no adjustment for multiple comparisons was applied. Given the small study size and number of pre- and post-test comparisons that were computed, the Type I error was likely inflated. As such, the results should be viewed as preliminary.

Third, the outcome data presented are collected by treating clinicians in the clinical setting and may therefore be less reliable than data collected in formal research settings. However, all staff are trained in the application of the tools. Therefore, this level of accuracy is likely as good as can be expected in the context of routine clinical care.

# 8

## Conclusions and Recommendations

Many people with an ABI will experience continence problems, which have considerable implications for their cost of care, independence, and quality of life. Yet continence remains poorly assessed and significantly under-managed in this population. Adequately managing continence should not only improve rehabilitation outcomes and increase independence but significantly reduce the burden on the healthcare budget.

This project was undertaken to decrease the cost of care, increase independence, and improve quality of life for clients with ABI receiving staged, community-based injury rehabilitation at the Brightwater Care Group (WA). The project had four primary objectives:

1. Investigate, review, and trial technology to support people to toilet more independently.
2. Identify opportunities for change in practice.
3. Determine the change in quality of life for residents using assistive toileting technologies.
4. Provide a final report and recommendations to the Insurance Commission and Brightwater.

The findings of this study indicate that intervention comprising a comprehensive continence assessment, individually tailored management, and ADs in the ABI population will improve functional independence, both in cognitive and physical domains. Intervention can also reduce care hours and thus cost. However, intervention did not positively impact client-reported quality of life. Continence practice can also be improved to deliver client-centred and multidisciplinary care. Across multiple levels of analysis, the importance of a client-centred and multidisciplinary approach to continence care was consistently identified. These findings have wide-ranging policy and practice implications, which should be taken into consideration when planning treatment and rehabilitation services.

**Moving forward, it is recommended the Insurance Commission, as the research funder:**

1. Engage with service providers to its clients with catastrophic injury and probable, uncertain, or complex incontinence, to ensure a comprehensive continence assessment is completed by a qualified continence specialist.
2. Consider how best to ensure future clients with catastrophic injury undergo early and regular comprehensive continence assessment.
3. Support industry-wide seminars/workshops on continence to improve sector-wide practice.

**Sector-wide recommendations include:**

1. Adopt a client-centred approach to continence care.
2. Review current policies and procedures against clinical practice guidelines.
3. Ensure standardised clinical documentation to enable the effective exchange of information between staff and to ensure continuity of care.
4. Improve continence management role clarity and understanding of roles.
5. Promote a multidisciplinary approach.
6. Increase staff education and training.
7. Support a multidisciplinary approach.

**Recommendations for future research include:**

1. Use larger samples of clients with ABI for replicability, generalisability, statistical significance, and effect sizes of findings from this study.
2. Replicate the study in an in-home setting and over longer time periods.
3. Examine the possible causes of the decline in HRQOL.
4. Examine the lived experiences of persons with ABI and incontinence to foster a client-centred approach.

**Continence and brain injury:  
Improving independence and quality of life, and reducing cost of care**

# Appendices

## Appendix 1: Costing Methodology for Valuation of Care

When converting the UK ROC algorithm to AUD specific to Western Australia, the following must be considered:

- The Insurance Commission of Western Australia (Insurance Commission) uses the National Disability Insurance Agency (NDIA) attendant care rates for carers looking after their clients.
- Only NDIA rates were used when converting the United Kingdom Rehabilitation Outcomes Collaborative (UK ROC) algorithm, as opposed to an average of the Insurance Commission and NDIA rates (National Disability Insurance Agency, 2018).
- Services are valued at different rates, i.e., domestic support is valued at a lower rate than nursing support.

### Packages:

- For domestic package hours, the “House Cleaning & Other Household Activities” NDIA rate was applied. This is described as performing essential house cleaning activities that the participant or client is not able to undertake.
- Attendant care (hour per daily, daily care) costs were calculated from the “Assistance with Self-Care Activities – Standard” NDIA rates inclusive of public holidays and weekend/penalty rates; where an average hourly rate inclusive of penalties was not available, this rate was calculated (inclusive of public holidays, Sunday and Saturday penalty rates).
- Waking Night-Time Care: the ‘Assistance with Self-Care - Active Overnight’ rate was applied. An average of standard and complex need rates was calculated.
- For 24-hour support, the NDIA average hourly rate was calculated using the “Assistance with Self-Care Activities – Standard” (daytime) plus the nightly rate from ‘Assistance with Self-Care - Night-Time Sleepover’.
- Skilled nursing care/trained care was calculated as the gap between standard attendant care and nursing costs per hour. As the NDIA does not fund nursing care, the relevant home nursing fee hourly rate from the Royal District Nursing Service (specific to WA; Silver Chain) was applied. Where an average hourly rate inclusive of penalties was not available, this rate was calculated (inclusive of public holidays, Sunday and Saturday penalty rates).

National Disability Insurance Agency. (2018). NDIS Price Guide Australian Capital Territory, Northern Territory, South Australia, Western Australia Valid from 1 July 2018. Retrieved from: <https://ndis.gov.au/medias/documents/price-guide-wa-201819-pdf/201819-Price-Guide-ACT-NT-SA-WA.pdf>

## Appendix 2: Additional Statistical Analyses

### NPCNA Data

Table 17 shows the median point estimates for overall NPDS dependency scores, weekly care hours, and average weekly cost at Time 0 and Time 3 for all care activities. The results of the Wilcoxon signed-rank tests are also given. Based on these results, there was a statistically significant change in overall care hours. No other significant differences were identified.

**Table 17. Changes in Continence/Toileting Dependency Scores, Total Care Hours, and Average Cost (AUD) over the Study Period (n=14)**

Outcome	Median (IQR)		Wilcoxon signed-rank test		
	Time 0	Time 3	Change	z	p
Dependency	24.5 (14.5, 36.5)	17.0 (9.8, 35.8)	7.5	-1.4	.167
Care hours	45.5 (31.9, 66.5)	34.1 (18.4, 63.9)	11.4	-2.41	.016
Weekly cost	\$8,026.5 (7,319.8, 12,058.8)	\$7,531.5 (5,980.5, 11,495.5)	495.0	-1.64	.100

**Note:**

1. IQR = interquartile range.

Table 18 shows the medians for NPDS dependency items relevant to toileting/continence, in addition to estimated total weekly care hours and the average cost of care per week at Time 0 and Time 3.

**Table 18. Overall Changes in Median NPCNA Data for Toileting and Continence from Time 0 to Time 3 (n=14)**

Outcome	Median (IQR)		Wilcoxon signed-rank test		
	Time 0	Time 3	Change	z	p
NPDS score					
Bladder (assistance)	3.0 (1.5, 4.0)	2.0 (0.0, 4.0)	1.0	-1.28	.202
Urinary incontinence	0.0 (0.0, 1.0)	0.5 (0.0, 1.25)	0.5	0.00	1.000
Bowel (assistance)	3.0 (1.5, 4.3)	3.0 (0.0, 4.0)	0.0	-0.74	.458
Faecal incontinence	0.0 (0.0, 0.5)	0.0 (0.0, 2.0)	0.0	-0.27	.785
<b>Total</b>	<b>6.0 (3.3, 9.3)</b>	<b>6.0 (1.5, 8.5)</b>	<b>0.0</b>	<b>-0.77</b>	<b>.439</b>
Care hours/week	17.5 (6.6, 24.5)	12.3 (0.0, 18.4)	5.2	-1.83	.067
Cost/week	\$7,340.0 (949.5, 11,812.3)	\$7,340.0 (0.0, 11,304.0)	0.0	-0.36	.721

**Note.**

1. IQR = interquartile range.

## Appendix 3: Cost of Consumable Items

Table 19. Cost of Consumable Products

Consumable	Total cost	Unit cost
Barrier cream		
Convacare Critic barrier cream	\$149.16	\$6.22
Convacare Critic barrier cream	\$192.24	\$16.02
Convacare Protact barrier cream	\$88.32	\$3.68
Sudocrem (125g)	\$11.33	-
Sudocrem (30g)	\$6.71	-
Sudocrem (30g, 6 per carton)	\$35.60	\$5.93
Bedpan		
Plastic	\$39.00	\$39.00
Slipper	\$31.00	\$31.00
Bottom wiper	\$72.60	\$72.60
Bottom wiper (Buckingham)	\$99.00	\$99.00
Long-handled shower sponge	\$15.40	\$15.40
Catheter	\$18.60	\$1.80
Catheter nightstand	\$12.00	\$12.00
Catheter strap	\$6.91	\$6.91
Continence pads		
Medium	\$71.68	\$1.12
Large	\$61.44	\$1.28
Extra large	\$74.88	\$1.56
Disposable sheets	\$79.00	\$0.79
Drainage bag (day)	\$5.30	\$0.53
Drainage bag (night)	\$8.06	\$0.80
Inserts		
Medium	\$33.66	\$0.17
Extra large	\$42.25	\$0.22
Pull up		
Medium	\$70.00	\$1.25
Large	\$76.16	\$1.36
Extra large	\$86.80	\$1.55
Skincare cleanser		
Microshield	\$148.00	\$25.00
Skin cleanser	\$36.36	\$6.06
Urine bag leg tube	\$53.00	\$5.30
Urinals		
Disposable	\$87.32	\$0.87
Spill proof	\$52.00	\$52.00
Urine specimen collection hats		
Urodome	\$99.00	\$3.30
Wipes		
Barrier wipes	\$28.00	-
Remover wipes	\$42.48	\$0.42

<b>Consumable</b>	<b>Total cost</b>	<b>Unit cost</b>
Wipes (Contiplan)	\$9.60	–
Wipes (Kwikmaster)	\$94.68	\$0.40
Wipes (Lifree)	\$35.88	\$2.99
<b>Other</b>		
Antiseptic hand gel	\$75.25	\$6.27
Apron	\$105.00	\$0.11
Body wash		
Avagard	\$70.75	\$7.80
GOJO Foam wash	\$66.03	\$22.00
Exam gloves		
Vinyl	\$5.08	\$0.05
Latex	6.95	\$0.07
Nitrate	\$12.35	\$0.25
GAMMEX (sterile)	\$110.50	\$2.20
Gown (water resistant)	\$61.00	\$1.22
Moisturiser	\$81.00	\$8.10
Shoe covers	\$41.45	\$0.04
Surgical facial mask	\$12.25	\$0.25
Toilet paper	\$30.74	\$0.65
Washcloths	\$94.68	\$0.40



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Brightwater

**Brightwater Care Group**

Brightwater House, Level 3  
355 Scarborough Beach Road  
Osborne Park WA 6017

**T** 08 9202 2800

**F** 08 9202 2801

**E** [welcome@brightwatergroup.com](mailto:welcome@brightwatergroup.com)

**W** [brightwatergroup.com](http://brightwatergroup.com)

ABN 23 445 460 050 ACN 612 921 632



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