





A new service model for older people living with alcohol related brain injury and complex behaviours as they transition into long-term residential aged care.

# The Wicking I and II final report

This report will discuss the synthesis, contrast and outcomes of the recently completed Wicking projects, two phases of explorative research trials conducted over ten years (The Wicking I Project 2006–2011¹ and the Wicking II Project 2012–2015). These projects investigated the effectiveness of specialised models of residential aged care in improving the life quality and wellbeing of older people (aged 50+ years) living with complex behaviours arising from a cognitive impairment of mixed aetiology including an alcohol-related brain injury.

The impetus behind this project was to explore, refine and advise on the most appropriate care options for clients who present residential aged care providers with some of the most extreme challenges to service delivery due to their highly complex, high-risk behavioural profiles. The care models explored in this research delivered individualised, integrated care response programs that incorporated residential, clinical, psychosocial and drug treatment strategies supported by a specialty team. The focus of this program was to support the attainment of life skills so as to enable the participants to establish and maintain housing stability, effectively breaking the cycle of recidivism into homelessness. Interwoven throughout this report are the stories of the journey that a number of participants travelled before, during and after their participation in the Wicking program.

Dr Alice Rota-Bartelink July 2016

### **Executive summary**

Australia rightly prides itself on a comprehensive social service system designed to safeguard the lifetime wellbeing of its people. For older Australians, these provisions are largely made through the \$17.5 billion currently spent annually on the aged care system.

Within this older cohort, there is a subsection recognised for behaviours so challenging and potentially destructive that they cannot be accommodated within mainstream aged care. Indeed, this cohort exists on the fringes of aged care, sapping disproportionate resources from multiple government agencies and portfolios including aged care, mental health, drug and alcohol, justice, hospital and community services, housing and homelessness.

The Wicking I & II projects were undertaken to address the issues of humane treatment, cost and effectiveness raised by systemic failures to improve outcomes for this subgroup. The commencing insight was that Wintringham, a specialist service combining expertise in homelessness and aged care, had developed care settings which, with to-be-established refinements and appropriate resourcing, could provide a comprehensive, permanent solution to the otherwise intractable and expensive problems generated by this group.

The Wicking model of residential care has been developed over two phases of a research project (the Wicking I and Wicking II projects), both of which were conducted under the auspices of Wintringham and funded by two successive JO & JR Wicking Trust grants. Both projects involved the 'recruitment' of older individuals living with multiple and complex needs, mental illness and substance abuse disorders. This group had experienced significant difficulty accessing appropriate services due, in part, to their reluctance to engage with service providers combined with their complex antisocial behaviours. The integration of these individuals into mainstream care services had a long history of failure.

Excessive drinking and poor nutrition over a long period can result in decreased blood flow or metabolism in the frontal lobes of the brain, leading to a specific form of dementia often described as frontal lobe dementia, alcohol-related dementia (ABD) or, more specifically, as an alcohol-related brain injury (ARBI). Unlike Alzheimer's disease, which affects a different area of the brain, people with ARBI do not tend to show signs of confusion or forgetfulness, often leading to the misconception that their behaviour is under their full control and understanding. As a result, people with ARBI are frequently labelled as difficult and are often vilified or punished for their actions. The management of behaviours associated with ARBI was a particular focus of both Wicking I & II.

Key components of both Wicking programs were intensive case management, neuropsychological assessment and individualised behaviour management planning and monitoring. Staff working with selected participants received additional training around behaviour management principles and diversional activity support to facilitate their participation in structured recreational activities.

The Wicking I project demonstrated that it is possible to successfully transition older people experiencing homelessness while living with ARBI and complex behaviours out of homelessness. However, with no evidence of comparable research reported in the literature, there was no way to measure the cost-effectiveness of this model beyond the control-group comparisons. This led to the genesis of the Wicking II project. A key aim of this project was to deliver intensive transition support program to participants through the process of adjustment and integration into an existing

specialist residential aged care facility. Beyond the economic rationale, the design of The Wicking II project was drawn from the successful psychosocial and learning outcomes of the Wicking I project.

The Wicking II project was developed to push the boundaries of the Wicking I model beyond its application within the confines of a small living environment to the relatively less prescribed, open living environment provided in a 60-bed Wintringham residential aged care facility. Selection criteria replicated that used for Wicking I project and the model also included intensive structured activity programs, behaviour modification strategies and individualised drinking and smoking harm minimisation programs.

### **Summary of outcomes**

#### 1. Transitional care model

One of the more significant outcomes that emerged from The Wicking I project was the program's potential to be packaged as a transitional care model from which participants would emerge with a high likelihood of successfully transitioning into a more traditional Wintringham aged care service. This outcome was beyond the initial expectations of the project, which essentially started out to provide a model that could break the cycle of homelessness and excessive use of emergency services. After receiving a minimum of 5 months of intensive specialised care, Wicking I model participants successfully transitioned out of the Wicking program into Wintringham residential care. The success of this 'step down' integration led to a greater understanding of what could be achieved by an intensive individualised support program.

### 2. Cost savings

Another striking outcome from the Wicking I project was the economic savings to government through the Wicking model as opposed to 'life on the streets'. By comparing the frequency of service usage for participants of The Wicking I model to those of a control group, a cost-to-government saving of approximately \$30 per person per day was calculated – a saving of approximately \$11,000 per participant per year.

#### 3. Structured Activity Program

As recommended through the outcomes of the Wicking I project, the structured activity program of the Wicking II project was more intense – attendant carers delivered 25 hours of one-on-one individualised structured activity support each week. The outcomes demonstrated that at the commencement of the program this level of support was effective and appropriate, with most participants successfully 'stepping down' in the level of support they required as their participation progressed. Most participants stabilised and concluded their participation with approximately 8 hours of support each week.

#### 4. Reduction in behaviours of concern

The support provided to Wicking II participants allowed them to significantly reduce their drinking levels. A 66% decrease in average alcohol consumption was, for the most part, attributed to an effectively administered controlled drinking program. Both the Wicking I and Wicking II projects demonstrated that the Wicking psychosocial model of care reduced the frequency of challenging behaviour, in particular observed intoxication. Further, both projects highlighted the importance of delivering set, predictable (and realistic) 'structures' such as Wintringham's alcohol and cigarette program. These structures are important tools to support clients with complex behaviour

### **Outcomes requiring further investigation**

### 1. Separate setting (Wicking I) or open setting (Wicking II)?

Wicking I demonstrated how to successfully transition participants from the self-contained setting for that project into regular Wintringham aged care. This suggested commencing, in Wicking II, with the integrated placement of participants into a Wintringham aged care setting. Interestingly, Wicking II project participants, in general, spent longer than the Wicking I participants in the Wicking program before transitioning into regular care. As a result, while the costs per participant per day were lower in the Wicking II project than Wicking I, when the requirement for longer periods of project participation were factored into the analysis, overall, the Wicking I project was the more cost-effective option. Additionally, some conflict arose between Wintringham aged care residents and the Wicking II project participants as the latter, who might reside in the room next door, were perceived to be receiving more and 'favoured' attention from their 'special' staff. We need to further test these indicators that Wicking II setting arrangements were less beneficial than the Wicking I separate setting.

Another trial in a separate (Wicking I style) setting is needed to test whether transition results into Wintringham aged care can be replicated. This would yield vital information on the most successful and cost-effective transition model.

### 2. How to recruit and train supportive, flexible and non-judgmental staff.

Both these projects were staffed by people who were recruited (often from within Wintringham) on criteria of supportiveness, flexibility and non-judgemental dispositions. These staff were critical to the success of the projects. In order to make the Wicking model for the transition of older people living with ARBI and complex behaviours into long-term residential aged care replicable, more work needs to be done on effective techniques for recruiting on these criteria. Additionally, a thorough documentation of training curricula needs to be undertaken.

Overall, participants who enrolled in both Wicking programs were observed to have fewer police encounters, fewer emergency presentations, less ambulance use and fewer days of hospital stay six months after enrolment compared to the six months before. All of this contributes to a decrease in resource use – a significant cost saving per participant to the health and justice departments. But more importantly, this group of individuals were successfully supported to break the cycle of homelessness and to improve their life quality and subjective wellbeing.

During the life of the Wicking II project, the Australian Government announced funding for severe behavioural response teams (SBRTs) – a mobile workforce of clinical experts providing timely advice to residential aged care providers when assistance is requested for people experiencing severe behavioural and psychological symptoms of dementia. Recognising its expertise with ARBI management, Wintringham has been recruited into a consortium headed by Hammond Care to run the national Dementia Behaviour Management Advisory Service (DBMAS) to be provided by Dementia Support Australia (DSA).

These are positive indicators of recognition at the national level of the need to address exactly the issues generated by the cohort studied in Wicking I & II.

The Wicking projects will contribute to a greater understanding of what is achievable when a highly supportive model of residential care is provided to people with alcohol related brain injury and complex behaviours. For the first time in Australia, this knowledge base is poised to inform government initiatives to provide a supportive, enabling and cost-contained future for such clients.

Bryan Lipmann, Phillip Goulding and Helen Small April 2017

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### **Glossary**

Action research The study of complex social processes by introducing changes iteratively into these

processes and observing their effects

Acquired brain injury Any type of brain damage that occurs after birth

Aged A person aged 50 years and older (as opposed to 'elderly', which usually refers to

people over 65 years of age)

Aged care Support and services provided to the aged population by government programs,

the community and voluntary sectors, and the private for-profit and not-for-profit

sectors

Alcohol-related

dementia

A form of dementia at the more severe end of the spectrum of ARBI that is clinically

different from Alzheimer's disease and vascular dementia

Alcohol-related brain damage/injury

A condition where individuals are affected by significant levels of cognitive impairment and behavioural disorder as a result of long-term alcohol abuse

Challenging behaviour 
Culturally abnormal behaviour that, directly or indirectly, seriously disrupts or

affects the lives or routines of other people or services

Cognition The mental action or process of acquiring knowledge and understanding through

thought, experience and the senses, including aspects such as awareness, memory,

perception, reasoning and judgement

Complex needs A person whose needs and behaviours challenge health, human services and

criminal justice systems, due to a combination of two or more factors, including mental illness, intellectual disability, acquired brain injury, physical disability, behavioural difficulties, social isolation, family dysfunction and drug and alcohol

misuse.

Dementia A syndrome associated with a range of diseases characterised by a progressive

impairment of brain functions, including cognitive skills, memory, perception,

personality and language.

Executive functioning The abilities of retrospective memory and prospective cognition for the promotion

of strategic planning, including the delaying of responses to enable the

consideration of options, consequences, strategic development and flexibility in

ideas.

Homelessness The absence of safe and secure housing and the marginalisation from social

networks and community services.

Neurocognitive

disorders

An acquired cognitive decline in one or more cognitive domains

Neurobehavioural

disorders

A group of conditions in which brain damage or dysfunction produces primarily

cognitive and behavioural change

Psychosocial The psychological development or adjustment of an individual in relation to his or

her social environment

Wicking I project The first of two projects funded by the JO and JR Wicking Trust administered by

ANZ Trustees and auspiced by Wintringham from 2007 to 2011, set in an

independent four-bedroom home in Flemington, Victoria.

Wicking II project The second of two projects funded by JO and JR Wicking Trust administered by

Equity Trustees and auspiced by Wintringham from 2012 to 2015, set in a 60-bed

residential aged care facility in Dandenong, Victoria.

Wicking model An evolving model of service delivery informed by action research that supports

the needs of older adults living with complex neurobehavioural disorders

Wicking program The day-to-day delivery of direct care services in support of participants actively

engaged in the Wicking Project.

Wintringham An organisation that provides aged care services targeted specifically at elderly

homeless men and women

### **Shortened forms**

ABCD Antecedent - Behaviour - Consequence - Discussion

ABI Acquired brain injury

ANOVA Analysis of variance

ARBI Alcohol-related brain injury

ARD Alcohol-related dementia

AUDIT Alcohol Use Disorders Identification Test

BDP Brain Disorders Program

CIQ Community Integration Questionnaire

COWAT Controlled Oral Word Association Test

DKEFS Delis Kaplan Executive Function System

HADS Hospital Anxiety & Depression Scale

HoNOS Health of the Nation Outcome Scales

HONOS Health of the Nation Outcome Scales

HVLT Hopkins Verbal Learning Task

NDSHS National Drug Strategy Household Survey

NPI Neuropsychiatric Inventory

OBS Overt Behaviour Scale

RCFT Rey Complex Figure Test

SWLS Satisfaction with Life Scale

WTAR Wechsler test of adult reading

### 1 Ageing, homelessness and alcohol dementia

### 1.1 Ageing and homelessness

There is a common assumption in our society that homelessness is caused by personal irresponsibility; it is often attributed to life choice, mental illness or substance abuse. When the person who is homeless is an older person living with multiple diagnoses, the experience of deprivation and stigmatisation can lead to significant barriers in accessing appropriate support services. Many have lost the life skills and confidence required to maintain independent living while they continue to struggle with poorly managed or completely neglected physical and mental illnesses. This ultimately leads to an increased reliance on costly hospitals, crisis and emergency support services or even permanent incarceration.

In the absence of appropriate support, this client population tend to cycle through repeated episodes of homelessness or living in substandard accommodation. This leads to an incremental decline in the individual's quality of life and their physical, social and mental wellbeing. Commonly accompanying these disabilities is an overlay of complex behaviour that may further alienate the individual from social inclusion. These people often experience difficulty negotiating complex service systems due to their cognitive or behavioural problems. In a service system that is reactive and not proactive, this inequity often results in premature ageing, permanent disablement or, ultimately, to an untimely death.

On census night in August 2011, 106,080 people were classified as homeless, of which 14% (about 14,850) were older than 55 years of age.<sup>2</sup> In response to increasing international attention on the need for a consistent definition of homelessness, the Australian census's statistical definition recently changed from a cultural classification to a definition that defines homelessness as 'home'-lessness, not just 'roof'-lessness. This definition emphasises the core elements of 'home', such as a sense of security, stability, privacy, safety and control over living space (Australian Bureau of Statistics, 2012).<sup>3</sup> This definition also aligns with international terminology, which had previously been identified using differing definitions and methodologies and over different time-scales.

A more practical classification of homelessness that is specific to the older population has been derived from recent research evidence. Within this population, the experience of homelessness is divided into three key life patterns:

- those experiencing chronic, long-term homelessness
- those who have recently become homeless
- those who are at risk of becoming homeless.

People who experience chronic, long-term or multiple exclusion homelessness<sup>4</sup> commonly have complex needs, including substance misuse and poor mental and physical health, and frequently have limitations to their cognitive capacity and levels of insight. Indeed, some people in this group have spent significant periods of their life in institutions including orphanages, prisons and mental health hospitals. They have experienced iterative homelessness and have accessed crisis accommodation, marginal housing and day centres.<sup>5</sup> Studies in Boston and San Francisco have also identified rates of acute health care use within this population (including emergency departments) that are two to four times higher than the general population over the age of 50.6

People becoming homeless for the first time later in life<sup>7,8,9,10</sup> receive less recognition. Close to 60% of participants in the Melbourne site of a three-nation study on the causes of homelessness among older people were identified as being homeless for the first time later in their lives.<sup>11</sup> For these people, the onset of a mental illness, widowhood, marital breakdown and financial difficulties following retirement were found to be triggers for becoming homeless.<sup>11</sup>. It has been identified that housing and support services are underutilised in this group8 and that the precarious living conditions of older people also places them at risk of becoming homeless. This recognition is crucial to prevent older people's homelessness and also to understand how the service sector can work cooperatively to keep older people housed.<sup>12,13</sup>

Older people considered to be at risk of homelessness due to their insecure tenure and poverty often do possess the skills to maintain independent housing; however, limited financial resources imposed by limited incomes (such as pensions) make it difficult to afford housing. This group generally have had a relative stable housing history as distinct from the previous group, and are often experiencing homelessness for the first time. Their tenure or housing stability is compromised due to such factors as affordability, accessibility and/or safety issues. Many people in this group tend to have limited or no contact with their families and consequentially lack informal advocacy and support resources. 14,15 For many, the loss of a spouse through death or separation is a trigger for their housing crisis, due to difficulties in paying rent as a result of loss of income. 16,17,18 Social isolation is experienced by many individuals within this group, and a large proportion experience difficulty accessing appropriate support services. 19,20 For example, older people (55 years plus) represented less than 6% of clients accessing specialist homelessness services based on a 2011–2012 database of people receiving such services. 21

This underrepresentation of older people seeking homelessness services must be considered when interpreting findings from homeless service data which, while important, cannot estimate the total number of homeless people at one point in time. The census, on the other hand, has developed a process of estimating homelessness by identifying those groups who, on balance, were most likely to be homeless based on a number of characteristics that identify different 'elements' of the definition of homelessness. Therefore, the census data offers a more accurate estimate of people who were likely to have been homeless at one point in time.<sup>22</sup>

Of the older cohort that does access homeless services, there are distinct differences in the reasons why they seek support. Reasons for younger (54 years and under) and older homeless clients (n=13,755) seeking support are shown in Table 1. The primary issues for women related to housing and domestic violence, with very little difference between age groups. For older men, the main reasons for seeking assistance were financial difficulties and concerns regarding housing, which they shared equally with young males. These findings elucidate that key strategic directions of service delivery for homeless service providers may be strongly influenced by the demand presented by younger clients, leaving older clients underserved.

Table 1 Number of people seeking assistance by age and gender, 2011–201221

Financial difficulties Housing affordability stress Housing crises Inadequate or inappropriate dwelling conditions Previous accommodation	1,292 354 590 636	17 5 8	14,372 4,851 12,514	11 4 10	1,453 381	21 5	11,523	13
stress Housing crises Inadequate or inappropriate dwelling conditions Previous accommodation	590	8	,			5	2 422	
Housing crises Inadequate or inappropriate dwelling conditions Previous accommodation	590	8	,			5	2 4 2 2	
Inadequate or inappropriate dwelling conditions Previous accommodation			12,514	10	020		3,132	4
inappropriate dwelling conditions Previous accommodation	636	9			830	12	11,164	13
dwelling conditions Previous accommodation	636	9						
Previous accommodation	636	9						
accommodation			9,728	8	771	11	7,366	8
ended	258	3	4,384	3	487	7	4,714	5
Time out from								
family/other								
situation	120	2	2,590	2	98	1	1,753	2
Relationship/family								
breakdown	206	3	6,460	5	190	3	4,736	5
Sexual Abuse			453				62	
Domestic and family								
violence	1,938	26	36,855	29	140	2	7,821	9
Non-family violence	65	1	797	1	35	1	376	
Mental health issues	139	2	1,228	1	194	3	1,739	2
Medical issues	161	2	605		282	4	647	1
Problematic drug or								
substance use	5		709	1	45	1	1,483	2
Problematic alcohol							,	
use	0		317		176	3	941	1
Employment								
difficulties			117		0		256	
Unemployment	0		159		0		263	
Problematic	·		200		· ·			
gambling	9		9		22		85	
Transition from			9				00	
custodial								
arrangements	0		461		76	1	2,297	3
Itinerant	63	1	1,387	1	189	3	1,746	2
Unable to return	05	_	1,507	_	103	3	1,740	2
home due to								
environmental								
reasons	21		448		48	1	440	1
Lack of family and/or	21		440		40	1	440	1
• •	116	2	1,208	1	150	2	1,005	1
community support Other	471	6	6,012	5	506	7	5,475	6
Not stated		12	20,950	5 16		11		20
Total	856 7,384	12	20,950 127,505	10	788 6,964	11	17,298 87,395	20

### 1.2 Ageing and disadvantage

There are many factors that influence the rate at which we age. Lifestyle is an obvious contributor; however, genetic, environmental, psychological and physiological factors can also influence the ageing process. Aged people who remain connected to, maintain or create new social networks achieve better health outcomes than those who are disengaged from society and social commitments.<sup>23</sup> Continued loneliness compounds the symptoms of stress and depression and negatively affects physical health and the ability to age well.<sup>24,25,26,27,28</sup> Many drugs, which may be abused by older people, can have long-term negative health consequences such as strokes, seizures

and acquired brain injury (ABI). All of these can impact daily functioning as well as changes in brain functioning and, subsequently, on decision making, mood, and memory.<sup>29</sup> Cognitive impairment associated with smoking and drinking has been identified as a risk factor for older people – health-promotion activities that assist in their reduction have demonstrated positive benefits to wellbeing and mental function<sup>30</sup> (also see 'Alcohol, injury and the ageing brain', below).

In the literature, there are many associations between homelessness and a high incidence of premature ageing.<sup>31,32,33</sup> However, much of the inference to premature ageing is based on life expectancies. Age-related mortality ratios reveal that homeless persons of all age groups have a higher risk of premature death than people of similar ages in the general population, particularly among vulnerable subgroups within the homeless population. The end result is a shorter life expectancy with an average age of death ranging between 42 and 52 years in Western countries that have an average life expectancy nearing 80 years of age.<sup>34,35,36</sup>

High-risk lifestyles and unsafe living environments can contribute to the higher incidence of premature or accidental death. There is a known link between early cognitive decline and poor physical health with modifiable lifestyle factors.<sup>37</sup> A person who has lived an impoverished life characterised by hardship and long periods of homelessness appears much older than their chronological age. They suffer multiple chronic illnesses that are often neglected as many are reluctant to seek timely, appropriate medical help.<sup>38</sup>

The population of older people who are experiencing homelessness constitute one of the most powerless and marginalised groups in society. The vast majority are transitorily supported by a range of agencies, including: homeless services delivering personal and social support and emergency and medium-term accommodation; alcohol and other drug treatment services; mental health services; and a range of other services<sup>39</sup>. However, many of these services often work independently from each other and clients may not always be referred to an appropriate service for support. Mainstream and specialist services alike struggle to provide appropriate care to vulnerable older people, particularly those who present with an overlay of complex or challenging behaviour. Often these services do not have the capacity to accommodate the person's life choices, resulting in increasing behavioural disturbances that further alienate the person from community care options.<sup>40</sup>

Older men and women from homeless and low socio-economic backgrounds often face disadvantage with respect to equity of access to quality health and aged care. Coupled with other significant social, health and psychosocial challenges, these individuals are at greater risk of a rapid decline in health and wellbeing, with subsequent premature ageing and mortality. As a consequence, many are in need of aged care at younger ages than the general population. The average age of residents in mainstream residential care in 2014 was 84.5 years<sup>41</sup> (85.8 for women and 81.6 years for men<sup>42</sup>), whereas in a specialised company providing residential age care to people experiencing homelessness (Wintringham), the average age of all clients in 2016 was 72.4 years (75.5 for women and 70.9 for men). This shows that aged care residents who have experienced significant levels of disadvantage are approximately 10 years younger than residents of mainstream residential aged care.

In 2014, 6400 people living in residential aged care were under the age of 65; the vast majority had some form of dementia or cognitive impairment.<sup>43</sup> It is not appropriate for a younger person with dementia or cognitive impairment to be isolated in a facility in which the activities and services

cater for older people. Sometimes, services are withdrawn due to the cognitive and behavioural issues associated with some clients because of occupational health and safety risks to workers and co-residents.<sup>44</sup> At the same time, there are limited options outside of residential aged care for younger people living with a cognitive impairment who require full time care and support. If an appropriate aged care placement is not found, these people very often become part of a cyclic pattern that commences when their health deteriorates to a point at which they lose the capacity to care for themselves. At this stage, they usually enter the hospital system. For most people, their care is managed, addictions and psychiatric conditions are treated and their physical and cognitive ability improve. Others, driven by fear or addiction, discharge themselves before treatment has been administered or concluded. A few are inappropriately discharged or ejected early because of their difficult, aggressive or challenging behaviour.

The people who do receive hospital treatment often need to remain in hospital for longer periods due to the inappropriateness of discharge to substandard accommodation settings, which cannot provide the required care support and levels of hygiene. Of those who improve to the point of discharge, many return to the community unsupported and commence the cycle again. Older homeless people often cannot comply with discharge instructions and follow-up appointments, particularly those with complex needs including psychiatric conditions, alcohol or drug problems and/or cognitive impairment.<sup>45</sup> The unfortunate consequence of this cyclic pattern of intermittent, crisis-driven interventions is the progressive and sometimes rapid deterioration in the person's psyche and physical health.

For these reasons, Australia (as with many other Western nations) has recognised people aged 50 years and older experiencing homelessness as having 'special needs' and therefore eligible to access and receive government-funded aged care services. <sup>46</sup> This in itself has created obstacles to the access and delivery of appropriate care to people who have aged physically but not psychologically and therefore do not easily assimilate within mainstream aged care populations. <sup>47</sup>

Providing secure, affordable and appropriate accommodation, in conjunction with support services, can not only postpone the need for entry into an aged care or nursing home, but can also encourage long-term positive health, psychosocial wellbeing and an increased sense of independence. Working with the elderly homeless presents particular problems for service delivery, in part because of premature ageing, combined with clients' general reluctance to accept services. This reluctance may stem from a determination to remain independent, but is more likely due to negative or demeaning past experiences with health and social service providers.

To develop services specifically for older homeless people, providers face limitations imposed by programmatic funding that is focused on meeting mainstream aged care needs. For more than 25 years, Wintringham (a not-for-profit welfare company) has successfully provided aged care services to elderly men and women (50 years and older) who have experienced homelessness or are at risk of becoming homeless in Melbourne, Victoria. Wintringham's unique service delivery model has evolved to incorporate flexible, tolerant and non-judgmental strategies to address a myriad of unique and diverse care needs. Many of these result from premature ageing (reflected in the high and early incidence of chronic illnesses) but, more significantly, also the complexity of behaviour associated with long-term mental illness, alcohol-related brain injury and homelessness. Wintringham's non-conventional approach has enabled it to grow while successfully supporting the needs of people for whom all other avenues of care have previously failed: people with little to no family; people with little to no financial means; and people for whom 'safety and trust' are

intangible concepts – in other words, people who currently do not fit neatly into any existing category of care.

Wintringham tailors services to younger residents' care needs, through a person-centred approach delivered through such innovations as community integration, recreation and harm-minimisation practices. Flexible service systems, integrated health and psychosocial services, provided by a multidisciplinary team, and client-centred care are fundamental factors to the success of this initiative. Engagement in a therapeutic relationship based on trust and the development of care plans that are influenced by the participant's own perception of what constitutes wellbeing and life quality are essential.

A comparative international study of the causes of new episodes of homelessness among people aged 50 years and over was undertaken in the Australia, the United States and England. Semi-structured questionnaires were used to collect information on the circumstances and problems that contributed to homelessness.<sup>51</sup> Wintringham, funded by the Australian Government Department of Family and Community Services, was the Australian partner in this study. In Melbourne, 125 recently homeless people were interviewed,<sup>11</sup> and the findings of this study have been used to illustrate the characteristics of the population. Table 2 lists the frequency with which various life factors were reported by key support workers as contributing to the recent episode of homelessness experienced by their older clients.

Table 2 Frequency of factors reported by case workers as having contributed to respondent's last episode of homelessness<sup>11</sup>

Factors	Frequency	Percentage
Heavy drinking	26	20.8
Physical health problems	22	17.6
Mental health problems	18	14.4
Breakdown of marital/cohabiting relationship	12	9.6
Accommodation sold/to be converted	7	5.6
Problems with other relatives living with respondent	6	4.8
Poor daily living skills	6	4.8
Death of spouse	3	2.4
Problems with other tenants	3	2.4
Left prison	3	2.4
Gambling	3	2.4
Respondent's anti-social behaviour	3	2.4
Housing unsuitable	2	1.6
End of tenure/lease	2	1.6
Moved elsewhere	2	1.6
Death of parent(s)	1	0.8
Problems with landlord/landlady	1	0.8
Had rent/mortgage arrears	1	0.8
Use of illegal drugs	1	0.8
Loss of job	1	0.8
No income	1	0.8
Other	1	0.8
Total	125	100.0

#### A man in turmoil

Whites of his eyes were alarmingly yellow.

Alcohol or family? With embarrassment and self-loathing, recalling the moment his wife asked him to choose. Such chronic addiction. A wavering desire to overcome. An immigrant feeling displaced from his culture, community and family. Desperation to regain his identity ... then reunite with his son. Chaotic, transient lifestyle, Special Residential Service's, couch surfing, crisis accommodation, hospital emergency departments, sleeping rough. Just wanting, dreaming of the chance to have a place of his own home again – Utopia! Believing that everything would work out when he did. Grow vegetables in his yard like he used to. Work in a kitchen or building site. A strong desire to return to what made him feel like the man he was – useful. Lost. Life roles gone.

Creative. Humble. Complex.

Damage to the brain rendering him unable to follow through and implement the steps to achieve the life he so desired. Self-sabotage in a flood of alcohol when positive progress toward goal realisation loomed tantalisingly close.

Two weeks off successfully completing a 16-week rehabilitation program. A setback leading to a detrimental cycle of heavy intoxication, sleeping rough and brief appearances in emergency departments. Discharging himself before staff arrived to assist further. Meetings, case conferences held in his absence, trying to find support options in the hope he would turn up in Emergency again before it was too late.

Little insight into his need for services and support. Rejection, eviction from services leaving limited options. Now sadly on paper gained a reputation of being violent, though not experienced by most. A respectful man who was extremely protective of women; however, when of the belief that he was being disrespected, he could lash out verbally, emotionally interspersed with pleads for respect. Crying, 'I am a human being'.

Worn down, sick, exhausted and finally in hospital long enough for staff to engage. Wintringham outreach support provided in the hospital. With all other supported accommodation options exhausted. Rejection influenced by his reputation. Finally set up in community flat. Tenuous decision influenced by desperation, respect and risk. Finally, 'his own place'. Supports established and often declined. Scheduled community support visits met with a vacant flat. Welfare checks were frequent. A positive future – his ultimate dream was tantalising him but his ability to follow through was lost. Intoxication and emergency presentations continued. Health declining.

Finally, the feared call came. No more meetings. No more anything. The last service he required ... 'Can you please come to identify his body?'

Overcome by addiction. Died alone, at least where he wanted, in his own home.

Entitlements taken for granted by so many within our ageing population, such as being well nourished, financially secure and living in stable housing, are not available to this group. Many have experienced childhood trauma in dysfunctional families, survived dangerous, unhealthy living environments, and have been exposed to multiple physical and psychological stresses and traumas throughout their lives. 52,53,54 With the added complexity of a lifelong disability or an acquired disability resulting from multiple diseases or injuries, it becomes almost impossible to determine whether the person's increased need for care and support comes as a consequence of premature ageing, their disability or disease.

Some of the more common issues facing aged people who are homeless that may impact their behaviour include:

- addressing acute and chronic medical conditions (e.g. diabetes, HIV infection, and heart and respiratory conditions, as well as drug detoxification and medical stabilisation of mental illnesses)
- having untreated or inadequately treated disabilities, such as hearing and/or vision impairment, lack of balance, or mobility impairments
- recognising cognitive problems, such as memory deficits, poor attention and concentration
- making the transition from institutions such as prison to the 'free world', including adapting survival skills that were functional in prison but are counterproductive outside the criminal justice system
- transitioning from inpatient hospitalisation, where people are free from responsibility for their own care, to having to assume full accountability for their care and their behaviour
- dealing with a history of trauma when sudden or unexpected events may trigger flashbacks or other responses that are perceived as inappropriate, and when symptoms of psychological trauma mimic, exaggerate or obscure the symptoms of other mental and substance use disorders.<sup>55</sup>

The term 'challenging behaviour' has become a clinical term. However, caution is needed to ensure that its use does not stigmatise the individual by separating the person from their behaviour. Challenging behaviour is a function of the interaction between the person and their current environment<sup>56</sup> and is defined as 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'.<sup>57</sup>

Complex or challenging behaviour within the population of people who are aged and homeless is frequent and often of high intensity. This can either directly or indirectly disrupt or affect the lives or routines of the person themselves, other people or support agencies. Often these behaviours interfere with the person's ability to learn, and may place them, others or property at risk of damage, injury or premature death. In the aged care residential setting, this includes other residents, neighbours, service staff, families and the broader community.

Due to these behaviours, ageing homeless populations have historically been stereotyped within the literature and professional groups as being stubborn, closed-minded and difficult to work with. 59,60 This can lead to discrimination in the selection process for admission to some services. Research has identified that a large proportion of older adults experiencing homelessness are difficult to locate and keep track of, to establish trusting relationships with and to interview. 61 Some attribute this to the person wanting to avoid stigmatisation, hospitalisation and institutionalisation. 62 For this reason, many avoid shelters and health care facilities and are wary of strangers. Furthermore, many older adults living in the shelter system and on the streets face victimisation by the younger homeless population. 59

Older homeless people have been described as 'feral' in that they become almost invisible to the rest of the community, learning through hard experience that it is often safer and wiser to withdraw and not draw attention to themselves.<sup>63</sup>

Bryan Lipmann, 2007

### 1.3 Alcohol, injury and the ageing brain

A compounding impediment to the delivery of appropriate aged care to the elderly person experiencing homelessness is the high prevalence of behaviours manifesting from neurocognitive disorders. Although the group of people living with an ABI constitute only a small proportion of the total number of aged care residents living with some form of cognitive impairment, they can present severe and ongoing challenges to support services. ABIs can cause symptoms similar to psychosis and dementia as well as significant problems with impulse control, social skills and selfawareness. These problems may manifest as agitated, difficult, disruptive, inappropriate and/or aggressive behaviour which may or may not be associated with a serious mental illness or disorder.<sup>64</sup> Research has shown that brain injury is highly prevalent within the older homeless population and that people experiencing homelessness report an exceptionally high rate of trauma exposure.65 As explained in the previous chapter, a large number of individuals within this population are wary and suspicious of service providers and are therefore unlikely to seek help or express concerns over their cognitive health. This leads to a significant under-reporting and underdiagnosing of cognitive impairment within this population. Alternatively, the behavioural manifestations of their impairment are misinterpreted as being deliberate or influenced by substance abuse.

Approximately half of homeless service users (58% of homeless men and 42% of homeless women) have a history of traumatic brain injury.<sup>66</sup> The most common of these are acquired brain injuries arising from long-term exposure to the harmful levels of alcohol intoxication and/or head trauma.<sup>67</sup> People living with multiple diagnoses, including mental illness, substance abuse and ABI, often find it difficult to access appropriate treatment/care services. These individuals can be slow to respond to questions and perform tasks due to slower thought processing speeds, and may have trouble negotiating complex systems due to cognitive or behavioural problems. Commonly accompanying these injuries is an overlay of complex behaviour that may further alienate the individual from social inclusion and accessing mainstream aged care support.<sup>68,69</sup>

In a three-nation study, 43% of the study's participants reported having issues with alcohol misuse (Figure 1).<sup>51</sup> Alcohol misuse problems were more commonly reported by men (48%) than women (28%), with nearly half the men admitting to heavy drinking or alcohol dependence. However, when case workers were questioned as to their client's level of alcohol consumption, there was evidence of significant underreporting of alcohol-related problems, with 77% of the male and 44% of the female participants being identified as under reporting.

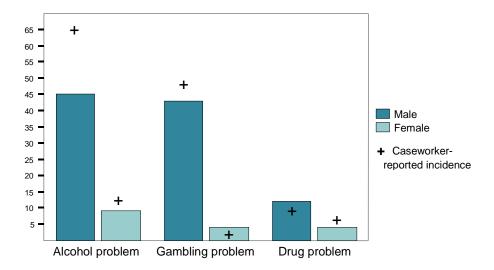


Figure 1 Frequency of respondent- and caseworker-reported addictive behaviour<sup>11</sup>

Of Wintringham's 1500 service users, approximately 20–30% of its residential and community aged care recipients have experienced, or are continuing to experience, an addiction to alcohol. Within this group, more than 50% are affected by an alcohol-related brain injury (ARBI) and very frequently this is accompanied by a traumatic brain injury. Aged people living with an ARBI receive less empathy and often attract more judgmental attitudes from the public than people living with age-related dementias. People living with an ARBI and ongoing addiction are often preoccupied with activities directed toward the procurement of alcohol. In the absence of adequate funds, the person may resort to whatever means possible to access alcohol, including criminal activity, aggressive stand-over tactics, begging or selling-on possessions of any significant value. Vulnerable co-residents can easily fall prey to such behaviours,

Chronic alcohol abuse can have long-lasting adverse effects on brain function and produce deficits ranging from mild cognitive impairment to dementia. Unlike Alzheimer's disease and other more common forms of dementia (which account for the vast majority of dementia cases in older aged people), alcohol-related cognitive impairment is more common in middle-aged people. The relationship between dementia and alcohol use is complex. Chronic heavy drinking may cause brain injury and give rise to alcohol-related dementia, a form of dementia that is clinically different from Alzheimer's disease and vascular dementia.

Much of the debate surrounding alcohol-related dementia encompasses whether it is possible to have a dementia that is the direct result of ethanol neurotoxicity (a primary alcoholic dementia) or whether the clinical presentation of dementia represents other underlying pathologies (such as thiamine deficiency) or multiple coexisting factors (such as neurotoxicity in combination with nutritional deficiencies). The neurotoxic effects of alcohol have been shown to cause white matter shrinkage and subsequent cognitive deficits that may be mediated directly through damage to brain structures or indirectly through malnutrition, metabolite toxicity, electrolyte imbalance, or accompanying physical illnesses and infection.<sup>72,73,74</sup> There is strong evidence that this damage may be partly consequential to liver injury.<sup>75</sup>

The effects of long-term excessive abuse of alcohol on the brain are diverse and are influenced by a wider range of other variables. These include the amount of alcohol consumed, the age at which the person began drinking, and the duration of drinking; the person's age, level of education, gender, genetic background, and family history of alcoholism; and neuropsychiatric risk factors such as alcohol exposure before birth and general health status. Research in this area has been confounded by factors that often accompany the lifestyles of people who drink alcohol excessively, such as experiencing traumatic head injury, other substance abuse co-morbidities, psychiatric disorders, and a higher rate of vascular risk factors.

Overall, physical health and mental health are influential factors in the detrimental effect that alcohol has on an individual, because comorbid medical, neurological and psychiatric conditions can interact to aggravate alcohol's effects on the brain and behaviour. Some researchers suggest that older people (aged 50 and older) are especially susceptible to the cumulative effects of long-term excessive drinking which accelerates ageing later in life. This is perhaps more correctly stated as, 'The effects of long-term alcohol abuse are disproportionately expressed in older drinkers'.<sup>78</sup>

Although there is evidence of ARBI being caused by direct alcohol neurotoxicity, there is an emerging body of evidence indicating that repeated episodes of subclinical Wernicke–Korsakoff's syndrome may partially account for the cognitive decline observed in long-term drinkers. <sup>79,80</sup> Wernicke's encephalopathy is an acute neurological disorder caused by thiamine (vitamin B1) deficiency. <sup>81,82</sup> Korsakoff's syndrome is characterised by profound amnesia, disorientation and frequent confabulation. Because Korsakoff's syndrome often follows Wernicke's encephalopathy, and both appear to share common pathological pathways, it has become convention to describe this continuum as Wernicke–Korsakoff's syndrome.

#### Needs met

After a colourful, transient lifestyle – an abundance of stories to tell. Confabulated or fact was irrelevant. No longer able to cope independently in community housing. Complex. Reportedly demanding. Needs unmet. Increasingly frequent ambulance call-outs, sometimes up to three calls in one day [ambulance chronology report confirming 58 call-outs in six-month period prior to commencing the Wicking program]. Lonely. Very lonely. Anxious about health. So much so he had taken to sleeping in his lounge room chair, he claimed for ease of access of ambulance drivers but in truth the evening alcohol consumption left him incapable of making it to his bedroom. Incontinent and frustrated. Consistent calls to community support agency as well as anyone else who would listen.

Upon the first visit he was excited. Excited by the possibility of a home forever that came with all the nursing support and care that he required. As well as company and recreational activities. 'We want you to think about this overnight and we'll call you in the morning for your decision.' 'Well, don't bother, I've already decided that I want this and I want it now!'

Transition. Nursing staff would check his blood pressure and temperature each morning to allay his fears of ill health. This gave him the confidence to continue with his day, knowing medical staff were there if required. A new room, bed, reading glasses and new teeth. Ambulance calls no longer required. Life was good. Sharing a big fat Stogie with the CEO.

Sadly, the years of self-neglect contributed to a progressive medical condition and care needs that increased beyond the capacity of the hostel. Multiple, repetitive seizures for a week. Ten to twenty years of memory were lost. 'Where are my kids? ... Where is my wife?' Care needs were no longer able to be met. Confused and angry and frequently lashing out.

Care staff would continue to visit and attempt to comfort P in hospital and in his new accommodation. They came armed with documented memories to provide comfort when he became confused. He just wanted them to take him home. (Also see vignette 'Dear P' in Section 4.5.7.)

Partial recovery of white matter injury can occur with abstinence from alcohol.<sup>83</sup> Magnetic resonance imaging studies indicate early reversibility of white matter shrinkage with an associated clinical improvement in cognitive and motor abilities.<sup>84</sup> The mechanism behind this recovery is thought to be disrupted if drinking is resumed.<sup>75</sup> The brain injury that occurs as a result of alcohol abuse therefore appears to have two components: one of permanent change, the other of transient, potentially reversible, change.<sup>85</sup>

ARBI is characterised by high rates of post treatment relapse, with more than 50% of individuals who were treated for their addiction resuming drinking at harmful levels within one year. 90, 91 This high rate of recidivism is thought to be strongly influenced by neurocognitive changes arising from the presence of frontal lobe injuries, such as disinhibition, poor working memory and decision making, and overall cognitive impairment. 92 For instance, these deficits may make it more difficult for an individual to initiate and engage with coping strategies in the face of urges or temptations associated with alcohol use. Similarly, it is possible that response inhibition difficulties might affect how easily an individual can resist an urge to go to the bar, socialise with friends who drink alcohol, or drink excessive amounts of alcohol. Several factors have been shown to diminish the likelihood of recovery of brain structure with sobriety, including old age, heavy alcohol consumption, concurrent hepatic disease, history of withdrawal seizures, malnutrition and concurrent smoking. 93

The true aetiology of alcohol-related dementia, and its differentiation from alcohol-related brain injury and alcohol-induced dementia, remains controversial and not fully understood in terms of terminology, epidemiology and pathophysiology.<sup>71</sup> The presence of an ARD is now identified as an alcohol-induced persisting dementia in the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV. The diagnostic criteria for this classification must fulfil conditions such as being alcohol-related and resulting in multiple cognitive deficits that may cause significant impairment in social or occupational functioning compared with previous levels of functioning.<sup>94</sup>

### 2 The Wicking I project review – model and outcomes

### 2.1 The Wicking I model

The Wicking I project designed and evaluated a 'stand-alone' model of care to support older people who had experienced homeless while living with an ARBI. The project, fully titled 'Older People Living with an Acquired Brain Injury and Associated Complex Behaviours: A Psychosocial Model of Care that Supports Long-term Residential Care Needs: (The Wicking Project)', commenced in October 2006 and was funded by a Major Strategic Initiative Grant from The JO & JR Wicking Trust which is managed by ANZ Trustees. The project was orchestrated and implemented by Wintringham Specialist Aged Care, a not-for-profit provider of aged care services to older people who are homeless or at risk of homelessness.

The Wicking I project was developed in three stages:

- Phase 1 involved an incubation stage of project development and an investigative stage leading
  to the production of an investigative report. The focus of these investigations was to determine
  which factors increase the likelihood that positive individual and systemic changes occur for
  this population.
- Phase 2 consisted of an 18-month demonstration pilot, the methodology of which was used to determine the effectiveness of the Wicking specialised model of residential care in appropriately supporting older people (≥ 50 years old) living with moderate levels of ARBI, high behavioural care needs and a history of homelessness or risk of homelessness.
- Phase 3 involved evaluating the Wicking trial and establishing project outcomes.

The project received ethical approval by the full panel of the Austin Health Human Ethics Committee (HREC Approved Project No: H2008/03097) and was overseen by highly regarded and esteemed members of an advisory committee representing academic and key service industries.

The Wicking I model of residential care (the Wicking program) was developed from the understanding that complex behaviours are often self-protective, defensive or responsive behaviours that occur as a result of unmet needs. Primarily, these behaviours are stimulated by a cognitive impairment that often accompanies acquired brain injuries. Irrespective of the presence of a brain injury or display of anti-social behaviour, Wintringham's core belief is that these individuals are entitled to receive care and support that is both appropriate to their needs and that will promote empowerment and independence.

The Wicking I project participant population consisted of individuals over the age of 50 who were living with an ARBI and had severely affected behaviours. These participants were housed and supported together in a Wintringham community home. Participants were selectively recruited for a history of homelessness, continued drinking and unsuccessful tenancies arising from behaviours associated with their ARBI.

Fourteen volunteer participants were allocated to either an intervention (household participant) or control (community group) group. Seven household participants took part in the supported residential trial using the Wicking program. During the 18-month trial, the average length of stay for household participants was 7.1 months, after which time they successfully transitioned into lower levels of specialised residential age care. Another seven participants continued to reside in

the community without receiving any additional research intervention beyond their participation in hour-long interviews once every three months. The community group pursued their normal lifestyle patterns and service use and served as a control group for the Wicking I model for which they were also placed on a waiting list. The pre-participatory demographic and behavioural profiles of all participants are shown in Figure 2 and Figure 3.

The Wicking program took place in a specially modified four-bedroom home neighbouring an existing Wintringham low-level residential aged care facility in Flemington, 4.5 kilometres from Melbourne's CBD. The intensive support model involved specialised 24/7 care (at a ratio of 1.5 carers to 4 participants) and individualised recreation and behaviour management plan implementation.

These initiatives were supported by a team of highly trained and skilled personnel including care and recreation workers, aged care specialists and neuropsychologists. Personnel were trained with specialist skills to support the complex needs of this resident population. All aspects of staff training and support, participant support and consultancy in behaviour management planning were provided by the project support team and neuropsychologist.

The key elements of the Wicking I project's intervention model, including a structured activity program, behaviour modification strategies and harm minimisation programs, are shown in **Error! Reference source not found.**. This information is compared with the key components of the Wicking II project's intervention model, discussed later in this report

Table 3 Key components of the intervention model used in the Wicking I project and the Wicking II project

Program model/program	Wicking I project	Wicking II project
Research methodology	Action research	Action research
Number of participants	7 Wicking program	14 Wicking program
	7 community control	
Project duration – operations	18 months	36 months
Average duration of participation - participants	7.5 months	7.1 months
Dwelling occupancy type	Stand-alone four-bedroom communal home	Integrated within a large 60-bed facility composed of shared areas and individual bedrooms
Support for activities of daily living, meals and medication	administered by Wicking house staff delivered by a team of 4 key staff (rotating roster 12hrs/day)	administered by facility care staff delivered by a team of 15 general staff (rotating roster 24hrs/day)
Recreation/structured activity	4 hours per participant per week delivered by one part-time staff member delivered 2 days per week \$15 individual recreation expenses allocated/week	25 hours per participant per week delivered by a team of 6 part-time dedicated Wicking staff delivered 7 days per week \$70 individual recreation expenses allocated/week
Neuropsychological support	6 hours initial assessment and reporting 30 minutes per participant per week	6 hours initial assessment and reporting 15 minutes per participant per week
Case management	managed informally by the facility manager and research staff	managed by a dedicated part-time case manager
Alcohol and cigarette program	Harm minimisation model delivered by way of individual alcohol and cigarette programs administered by Wicking I staff	Harm minimisation model delivered by way of individual alcohol and cigarette programs administered by facility care staff
Behaviour modification strategy	using the ABCD behaviour management model	using the ABCD behaviour management model
	reviewed monthly	reviewed weekly
Staff training – behaviour	delivered by a neuropsychologist	delivered by research staff
management/participant review	2 × 4 hr sessions initially	2 × 4 hr sessions initially
	2 × 2hr per month	2 × 3 hr sessions per month

### 2.1.1 Structured activity/recreation programs

The Wicking recreation program was characterised by a process that helped participants pursue any desired recreational interest or life choice. Recreation staff spent time with each participant, identifying their interests and determining barriers restricting them from participating. The final stage in this process involved removing these barriers through inventive and innovative approaches designed not to impact significantly on enjoyment rewards. Much of the program was focussed on outdoor or community-based activities. Wicking program participants were initially reluctant to participate in such a structured activity program. However, through a persistent and skilled approach, levels of rapport, engagement and participation slowly improved to a point where the program became an effective tool in diverting participants away from alcohol-seeking activities to more enjoyable, rewarding and sustainable pursuits.

#### 2.1.2 Behaviour modification programs

The breadth and complexity of issues presented to staff when providing care to this client group was exceptional. Behaviour modification strategies were influenced by issues arising from diminished capacity, memory loss, coexisting mental illnesses, entrenched self-protective behavioural traits and personality disorders. Coping effectively with behavioural problems required the identification and acknowledgment of each participant's deficits. A comprehensive neuropsychological assessment was pivotal to better understanding neurological and cognitive strengths and weaknesses. The determination of overall risk associated with a behaviour had to be balanced with interventions that assured options, rights and dignity. For example, responses to sexually driven behaviours were considered with respect to human rights issues such as privacy, confidentiality, respect and disclosure.

The ABCD approach (Antecedent – Behaviour – Consequence – Discussion) was used in the Wicking program to develop behaviour management plans. This cognitive behaviour theory builds on the knowledge that if the consequence of a behaviour is inappropriately managed, the behaviour may escalate and in turn trigger other more extreme negative behaviour responses. The ABCD model identifies triggers or antecedents for the behaviour, builds an understanding as to what the individual is attempting to communicate through this behaviour and guides the systematic adaptation or modification of the influencing environment and/or interactions through a continuous improvement cycle.

#### 2.1.3 Alcohol and cigarette programs

Many people living with an extended history of addiction and an alcohol-related brain injury are either unable or unwilling to 'rehabilitate' or abstain from alcohol. This is especially true for those with entrenched patterns of substance abuse. The requirement to maintain abstinence within a 'dry' residential facility commonly leads to a daily pattern of heavy alcohol consumption immediately before entering the facility, followed by seeking alcohol early in the morning, to avoid substance withdrawal. This behaviour places the individual at significant risk of physical harm though alcohol-seeking activities, withdrawal or while intoxicated on the streets.

Wintringham views the issue of drinking in social justice terms, whereby the person has the right to choose to continue drink and/or smoke provided that the behaviour does not impact negatively upon others. Therefore, support focuses on reducing the harm and accumulative debt that can often result. Harm minimisation is a policy designed to decrease the adverse consequences of substance use without the requirement of abstinence. The theory stems from acceptance of the fact that a person should not be expected to suddenly attain and maintain sobriety as mandated by the majority of Australian residential care services.

The practice of harm minimisation allows the individual to continue drinking while offering a safe, supportive atmosphere in which strategies are in place to assist the resident to gradually reduce or to effectively manage their drinking levels. Individual care plans, including budgets, are developed to manage the severity or frequency of harmful drinking. The '14-day cycle' budget process is undertaken with careful consideration to residents, ensuring involvement and empowerment in decision making. Alcohol and cigarettes are purchased and decanted into the appropriate daily quantities. Staff administer the supplies using a medication style treatment chart. For clients who excessively consume alcohol or cigarettes, or gamble, and are unwilling to negotiate a sustainable

approach to consumption, the appointment of an administrator is often seen as an effective tool of last resort in managing personal expenditure as a means of managing these addictions.

The provision of alcohol in the form of a controlled drinking and or smoking program had a significant positive influence on the behavioural manifestations of Wicking program participants. It provided respite from daily hardship resulting from not knowing when and how the next drink or cigarette was to be acquired. How will they get the money? How long will they need to scour the footpaths in order to collect enough discarded cigarette butts? Will they face another day wracked with the symptoms of withdrawal? For many, the introduction of a controlled program presented the first opportunity in a very long while in which the choice to forgo a meal in place of alcohol or cigarettes did not have to be made. The drivers of behaviours such as begging, borrowing or stealing were effectively removed.

Through such initiatives, participants were supported to conduct their lives as they wished, with the proviso that their lifestyle choice did not negatively impact the lives of others. The result was a highly personalised program that balanced the needs of each participant with the resources available, while taking into account the impact and risk to their health and wellbeing through continued addictive behaviour. Encouragement and support was provided to participants to establish the skills and confidence required to make best use of the recreation and diversional structured activities.

### 3 The Wicking I project findings

### 3.1 Major points of learning

#### 3.1.1 Participant demographics

The average age of participants in the Wicking I program was 56 years (±8 years). All participants had experienced periods of homelessness, most of which extended across several years. All were single and the majority were divorced or separated. Half of the participants lived alone, mostly in public housing (Figure 2). The majority of participants had no regular contact with their families and were under administration orders administered by State Trustees. Just under half were under guardianship orders with a state-appointed advocate guardian through the Office of the Public Advocate.

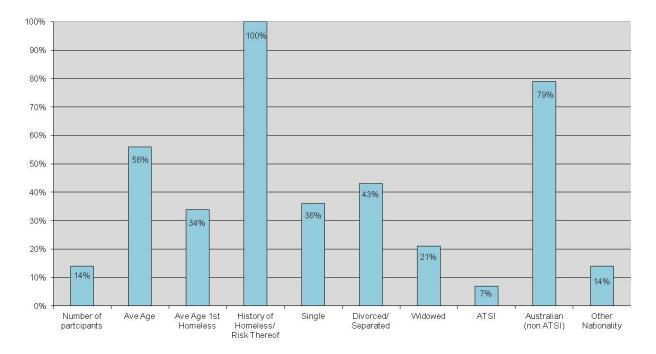


Figure 2 Demographic data for the Wicking I project participants

The nature of challenging behaviour exhibited by Wicking I project participants was rarely accurately self-reported. Estimates of frequency data were therefore reliant on third party reports from neighbours, service providers, etc. The most frequent categories of behaviour exhibited were verbal aggression and socially inappropriate behaviours (Figure 3). These behaviours in various forms were reported for all project participants.

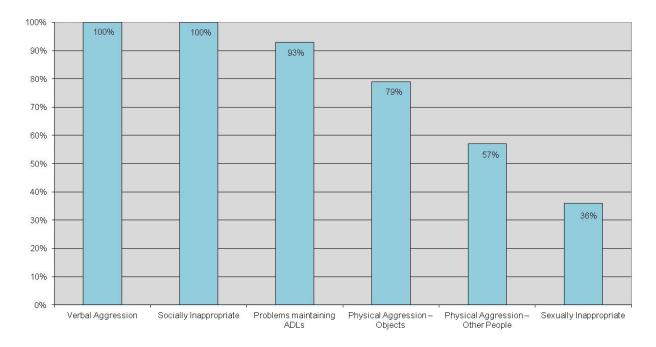


Figure 3 Percentage of Wicking I project participants exhibiting challenging behaviour before the project (n =14)

## 3.1.2 Transitional program

One of the more significant outcomes from the Wicking I project trial was the model's potential to be packaged as a transitional care model from which participants would emerge with high likelihood of successfully transitioning into the mainstream specialist aged care. This outcome was beyond the initial expectations of the project: what was originally expected to be a long-term residential care solution for only a few became a model that could potentially break the cycle of homelessness and excessive use of emergency services for many. After receiving a minimum of five months' intensive specialised care, Wicking model participants successfully transitioned out of the Wicking program into Wintringham residential care. The success of this 'step down' integration led to a greater understanding of what can be achieved through an intensive individualised support program.

#### 3.1.3 Cost benefits

Another striking outcome of this project were the savings to government achieved through the Wicking model as opposed to 'life on the streets'. By comparing the frequency of service usage for participants of the Wicking model to those of the control group, a cost-to-government saving of approximately \$30 per person per day was calculated (Table 4). This is a saving of approximately \$11,000 per participant per year.

Table 4 Cost-to-government comparisons for service delivery to Wicking participants compared with community participants\*

Community and aged care services	Wicking participant episode frequency+	Community participant episode frequency~	Cost (\$) per day/occasion#^	Wicking participant accumulative cost (\$)	Community participant accumulative cost (\$)
Crisis accommodation	0	7	138.0096	0	966.00
Specialised residential aged care	1106	0	186.6897	206,468.08	0
Public housing		158	16.5098	0	2607.00
Supported residential service	0	1056	8.4099	0	8870.40
Rent assistance	0	1489	7.93	0	11,807.77
Case management - community aged care package (CACP)	0	1067	36.07100	0	38,486.69
Multiple and complex needs initiative (MACNI-DHS)	0	552	512.34	0	282,811.68
Regional mental health case management	0	552	8.59101	0	47,41.68
Home and community care services	0	990	5.14	0	5088.60
Police attendance	6	33	164.17102	985.02	5417.61
Police overnight lockup	0	2	145.69	0	291.38
Ambulance attend	1	65	637.16103	637.16	41,415.40
Public hospital, Emergency	9	61	406.39	3657.51	24,789.79
Public hospital bed - general	5	36	649.66104	3248.30	23,387.76
Public hospital bed - psychiatric	0	40	860.62105	0	34,424.80
GP visits	30	20	41.65	1249.50	833.00
Alcohol detox unit	0	10	1082.40	0	10824.00
Total expenditure (\$) Cost per person/day				216,245.57 \$195.52	496,763.56 \$224.98

Notes: \* Frequency data based on four Wicking model participants and four community participants over an accumulative timeframe. +Based on 1106 accumulative days. ~ Based on 2208 accumulative days. # This table shows the estimated amounts provided by the Australian, state and local government authorities and by the non-government sector to fund expenditure on services relating to complex needs clients. ^All costs have been adjusted for CPI inflation rates 1999–2009.

#### 3.1.4 Mental health service engagement

The Wicking experience demonstrated that even the most skilled professionals were unsuccessful in navigating the bureaucratic red tape that restricts access to appropriate mental health services. Improved understanding and acceptance is required at all government levels on the need for specialist psychiatric support to assist older people living with coexisting mental illness and ARBIs. Secondary consultation was the only effective strategy in convincing regional mental health services of the existence of underlying mental health disorders among Wicking participants, thereby achieving acceptance for service eligibility. Within the Wicking household, major incidents of violence could be averted with expeditious access to appropriate mental health support.

# 3.1.5 Alcohol-related brain injury and complex behaviour

The person with an ARBI most commonly presents with damage to the frontal lobes of their brain characterised by poor decision making and increased impulsivity. This manifests with the person

readily engaging in inappropriate or high-risk behaviours in the absence of being able to regulate these behaviours, including a low resistance to the urge to drink.

Due to the dynamic nature of behaviours presented by people living with an ARBI, the importance of routine and consistency in their daily lives must be balanced with the need for staff to be adaptive, inventive and sometimes non-conventional in the provision of appropriate care and support. Staff needed to be constantly mindful that challenging behaviours occur as a direct result of the individual's unmet needs arising from their brain injury, and not to personalise the resultant behaviour. Each new participant brought with them a new mix of challenges and sometimes an entirely new set of resource requirements.

#### 3.1.6 Emergency planning and service relationships

The complexity of behaviour that frequently accompanies an ARBI can prove difficult to support, but when these behaviours were exasperated by episodes of intoxication, the effects can be extreme to the point of critical risk. This risk is evident in the frequency of emergency service usage for participants prior to their involvement in the program (Figure 4). Wicking staff required training on how to identify the point at which they needed to withdraw themselves and others from high-risk situations and the manner in which to do so safely. Policies and procedures around staff and resident safety and protection at times of violence and aggression required constant evaluation and review for their effectiveness following such incidents, as well as measures to support psychological wellbeing. In the Wicking model police from the local station attended residents' meetings in friendly 'meet and greet' sessions with participants as a proactive 'positive community policing' initiative.

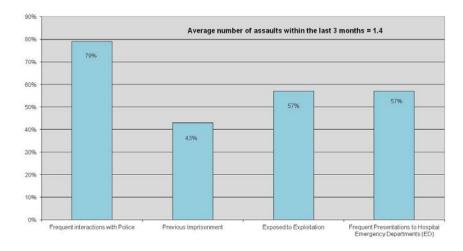


Figure 4 Percentage of Wicking participants who had interactions with justice and emergency services before participating in the program

# 3.1.7 Drinking and smoking culture

The culture around drinking and smoking within this client population works to ensure that there is always a way to access additional alcohol and cigarettes, if needed.

## Strategies included:

- theft of alcohol or consumption of large quantities of alcohol on the premises of supermarkets or bottle shops
- theft of goods that could later be returned for a cash refund, sold or pawned

- begging or busking for money and cigarettes
- stowing away excess alcohol for later consumption
- butt stooping collection of discarded cigarette butts
- pooling/sharing of resources (alcohol, cigarettes, money)
- purchasing cheap alcohol sold in large quantities to share
- loans in alcohol/cigarettes made for future returns 'helping out a mate'.

A consequence of the drinking culture was that when it was mixed with memory loss and impulsivity, episodes of intoxication frequently resulted in aggression and physical violence.

#### 3.1.8 Addiction to other drugs

The behaviour of a person who engaged in illicit drug use was markedly different from that of a person addicted to alcohol and tobacco alone, demonstrating a different set of support needs. It was therefore cautioned to carefully consider the inclusion of individuals with an illicit drug addiction in a care model designed specifically to support people living with an ARBI.

# 3.1.9 Neuropsychological involvement

An intensive support model focused on psychosocial rehabilitation such as the Wicking I project would not be successful without ongoing, high-quality neuropsychological support through the provision of neuropsychological assessments, staff training, participant behaviour management planning and implementation, counselling of staff and participants, attendance at resident and staff meetings and ongoing input into adaptive program development.

# 3.1.10Selection protocol

Participant characteristics that contributed to major incidents of concern included:

- low level of acceptance of a need for assistance/help
- ongoing instability in mental health (chronic psychotic symptoms), anti-social traits, ideations
- non-compliance with antipsychotic medication for those not on a community treatment order (CTO)
- a fervent desire for freedom and independence of choice and control which when achieved would rapidly lead to a spiralling decline in health and wellbeing
- a vehement dislike of rules and restrictions
- a younger cohort with greater levels of mobility, speed and physical strength
- ongoing addictions to other drugs.

# 3.1.11Eligibility for disability service support

Irrespective of the contributing aetiologies, all participants of the Wicking I project had a demonstrable disability. Specifically, they had an ABI according to the criteria in the Victorian (Australia) Disability Act 2006 that is:

- (i) permanent
- (ii) causes a substantially reduced capacity for self-management in a wide range of areas of everyday life, and
- (iii) requires significant ongoing or long term episodic support, and
- (iv) not related to: (1) ageing; (2) an intellectual disability; or (3) a developmental delay.

Most participants were referred to the program because they were unable to manage independent living. When unsupported, most participants were unable to regulate their alcohol intake, resulting

in drinking at very high levels, which placed their health and safety at risk. When drinking heavily, they were in frequent contact with the police, ambulance and hospitals; most had been blacklisted or banned from services and evicted from their accommodation due to alcohol-related behaviour.

The Wicking experience was that applications seeking eligibility for disability support funding followed a long and tedious process. These applications were made on behalf of the Wicking model participants with the aim of accessing individual support packages (ISPs). These packages were sought to purchase additional attendant care support to augment community–based structured activity programs after completion of the Wicking program. All but one application was unsuccessful due to bureaucratic red tape or eligibility criteria that were impossible to meet.

Successful navigation through the application process required a minimum of six months' administrative shuffling. Applications demanded the involvement of key personnel who possessed not only an integral knowledge of the application process and specific language intrinsic to disability services but who were also able to interpret the effects of the client's diminished cognitive capacity on social and physical functioning. These barriers and delays have been shown to have a detrimental impact on the lives of people who are often tenuously balanced between life and death.

## 3.1.12Wicking I project evaluation outcomes

Wintringham worked in conjunction with the Brain Disorders Program at Austin Health in evaluating this project. Clinically validated measures and frequency data were collected for all Wicking I project participants throughout the project. Multivariate tests revealed that for Wicking model participants, there were statistically significant reductions in the levels of anxiety and depression (Figure 5), problematic drinking and the number or alcoholic beverages consumed each day (Figure 6) and a significant increase in productivity levels. A clinically significant reduction was also measured in the total amount of cigarettes consumed each day. Notable, yet not statistically significant, group differences present at the outset of the project can be explained by the recruitment strategy whereby participants with the greatest need or those experiencing the greatest episode of life crisis were offered a position in the Wicking household.

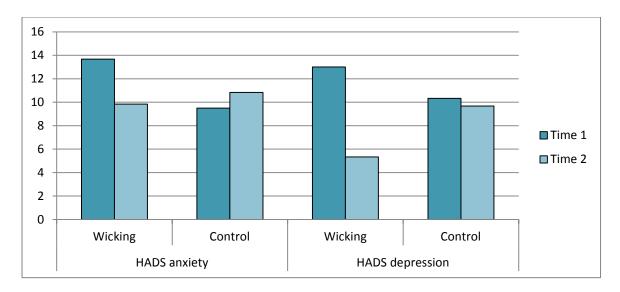


Figure 5 Hospital Anxiety and Depression Scale (HADS)

Anxiety assessment (Main effect – group F=0.30, p=0.60, Main effect – time F= 2.13, p=0.18, Interaction F= 9.08, p=0.01, Main effect – Wicking group by time F=7.50, p=0.04, Control group by time F=1.82, p=0.24) – Depression assessment (Main effect – group F=0.08, p=0.79 Main effect – time F= 11.16, p=<0.01, Interaction F= 7.88, p=0.02, Main effect – Wicking group by time F=33.06, p=0.002, Control group by time F=0.10, p=0.77)

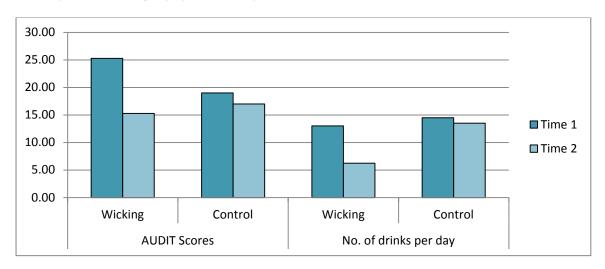


Figure 6 Alcohol consumption - Alcohol Use Disorders Identification Test (AUDIT)

(Main effect – group F= 0.16 , p=0.70, Main effect – time F=13.76, p=<0.01, Interaction effect F= 6.114, p=0.03, Main effect – Wicking group by time F= 5.72, p=0.03, Control group by time F= 0.16, p=0.60) - The Number of Drinks Consumed per Day (Main effect – group F=1.14, p=0.31, Main effect – time F= 13.53, p=<0.01, Interaction F= 8.03, p=0.02, Main effect – Wicking group by time F=1.24, P=0.32).

In addition to positive changes in psychological health, the general health of the Wicking model participants also improved significantly and was successfully maintained compared to that of the community control participants for the duration of the project (Figure 7). The state of wellbeing and life quality improved for the Wicking models participants throughout the project whereas it remained unchanged or deteriorated for the community participants, reflected in the changes in the number of valued life roles.

All participants underwent neuropsychological assessments at the commencement and completion of the project. No statistically significant differences were found; however, Wicking project

participants did perform marginally better overall as indicated by fewer participants showing deterioration and one participant demonstrating mild cognitive improvement.

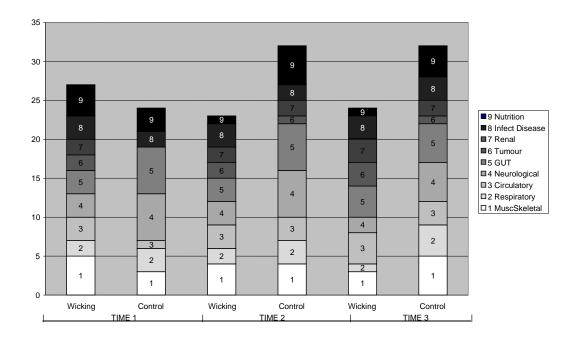


Figure 7 Changes in general health conditions for Wicking model and community control participants (Time 1-Outset, Time 2 - 9 months, Time 3 -18 months)

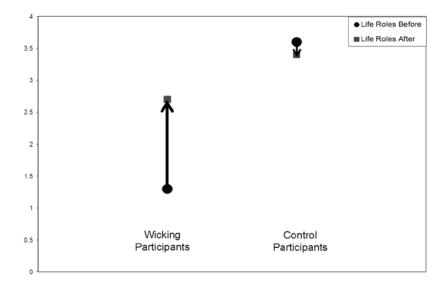


Figure 8 Changes in the number of valued life roles based on the Life Role Participation Survey

During their term of residency, behaviour frequency data was collected. Over the first five months of residency, significant changes were noted in the pattern of behaviour, particularly in the number of times participants were observed being intoxicated and verbally aggressive. A graph showing the total number of challenging behaviours recorded over time is shown in Figure 9, with a characteristic hill-shaped curve for all behaviours of concern. This finding educes a significant point of learning for the introduction of new residents exhibiting complex behaviour into new residential

care environments – staff can anticipate and plan for a peak in the frequency of incidents resulting from these behaviours approximately 3 months after taking up residency.

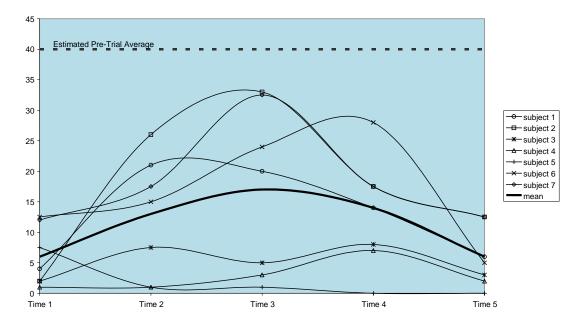


Figure 9 Frequency of incidents of challenging behaviours overall among Wicking model participants (F= 4.820, p=0.008)

Housing and support models are often based on the assumption that older clients require a static or increasing level of support without considering their potential for transition into other, less intensive residential care environments. Participants often spoke of the desire to move to other accommodation settings; many were looking for settings offering greater levels of independence and less support while some accepted that they temporarily required higher levels of support until such time that greater levels of health and independence were achieved.

The Wicking I project participant outcomes demonstrated that higher levels of depression were significantly associated with a lower number of meaningful life roles and a higher level of problematic drinking. Higher levels of anxiety were also significantly associated with higher levels of problematic drinking. This study also showed that an inverse relationship existed between life satisfaction and alcohol drinking patterns. Increases in the level of social integration and productivity were significantly associated with decreases in problematic drinking. Lower life satisfaction levels were recorded for participants experiencing higher levels of problematic drinking.

Increased levels of home integration (identifying with oneself as being an integral member of a household) were significantly associated with a reduction in smoking. This finding could be attributed to a reduction in the level of boredom through the engagement of purposeful activity, but could equally be attributed to the noted reduction in the level of anxiety and depression and improved wellbeing. This finding is reinforced by the significant positive relationship found to exist between higher levels of overt behaviour and a greater number of cigarettes smoked each day.

For formerly homeless older adults, the most formidable barrier to housing transition is the scarcity of affordable, appropriate accommodation and support options available. Another consideration is the vulnerability due to change arising the move itself. Identifying patterns of

behavioural change for participants in the Wicking I project as they transitioned into residential aged care was one of the most practical outcomes of the project. The application of this knowledge informs the process of admission of older people experiencing homelessness into residential aged care environments and the realistic expectation of behavioural change. Transitions should be trialled and barriers removed, with assurances that people can decide to return to their original housing situation should the transition prove unsuccessful. Services must also be mindful of the characteristic changes noted in behaviour frequency and intensity over the first six months of tenancy.

# 4 The Wicking II project

The Wicking I project demonstrated that is was possible to successfully transition older people experiencing homelessness while living with an ARBI and complex behaviours out of homelessness and into a stand-alone, intensely supported small facility. However, with no evidence of comparable research reported in the literature, there was no way to determine the cost-effectiveness of this model beyond the economic data gleaned from service usage comparisons with control group participants. If the Wicking model was to ultimately be promoted as an economically viable long-term program, further investigation into the effectiveness of an alternative model of service delivery was warranted. This lead to the genesis of the Wicking II project, for which the key aim was to deliver intensive transition support to participants through adjustment and integration into an existing specialist residential aged care facility.

Beyond the economic rationale, the design of the Wicking II project was drawn from the successful psychosocial outcomes and learning of the Wicking I project. The Wicking II project was developed to push the boundaries of the Wicking I model beyond the confines of a small, yet resource-intensive conjugate living environment to the relatively less prescribed, open living environment provided in a 60-bed Wintringham residential aged care facility. The challenge was to apply an intensive support program developed in a controlled environment shared by a small number of people residing together, to a small number of participants distributed within a larger population of elderly residents representing diverse and varied cultures, backgrounds and clinical and behavioural support needs.

# 4.1 Project methodology

#### 4.1.1 Aims

The primary focus of this project was on the provision of highly skilled specialist consultancy services to people living with highly complex needs and their caregivers.

# 4.1.1.1 Overall project aims

- a) To trial the application of a novel neurobehavioural model within the archetypical Wintringham residential care environment.
- b) To evaluate the effectiveness of a trial implementing the Wicking model delivered as a sixmonth intensive consultancy program to support older people with a history of homelessness, ARBI and complex behaviours to transition into, and live autonomously within, the Wintringham residential aged care environment.
- c) To document, evaluate and report on the outcomes of this project.
- d) To determine the efficacy of a six-month intervention timeframe in achieving articipant outcome aims (listed below).
- e) To complete economic modelling comparing the Wicking II project service delivery model to other possible life pathways commonly associated with aged homelessness (e.g. imprisonment, secure locked facilities, emergency hospital/psychiatric care).
- f) To maintain the gains achieved through participation in the Wicking II project beyond the cessation of the program.

#### 4.1.1.2 Research aims

a) Document the demographic backgrounds of participants in the Wicking II project.

- b) Assess the effectiveness of the Wicking model in achieving positive outcomes for participants in the Wicking II project.
- c) Understand the processes and mechanisms through which the Wicking project influences participant outcomes.
- d) Assess the knowledge and confidence with which staff work with participants in the Wicking project.
- e) Estimate the cost-effectiveness of the Wicking project.

# **4.1.1.3** Participant outcome aims

Upon the completion of the program it was our aim that each project participant would experience:

- a) increased participation in social and community-based activities and independence of access
- b) increased accessibility of local community health and wellbeing support services
- c) improved physical health through improved and timely access to general and specialist medical care, as well as improved diet and increased physical exercise
- d) improved psychological wellness, social and living skills and decreased psychological distress
- e) improved overall life quality
- f) reduced hospitalisation rates, frequency and duration of time spent in hospital and emergency departments
- g) reduced number of forensic engagements
- h) reduced frequency and intensity of challenging behaviour exhibited
- i) reduced reliance on carer-supported activity participation
- j) an ability to maintain the gains achieved through participation in the Wicking II project beyond the cessation of the program.

#### 4.1.1.4 Systemic aims

The broader systemic outcomes that the project had aimed to achieve were:

- a) systemic change demonstrated by an increased awareness among policy makers of the gaps that exist within the current service system in the delivery of appropriate specialised services to meet the needs of older people with ABI
- b) provision of evidence that the Wicking program can offer a specialised model of care to successfully address this gap through the delivery of an appropriate long-term residential care option that has been demonstrated to work
- c) provision of evidence through economic modelling that demonstrates that the implementation of this specialised model is more viable than current intervention strategies
- d) to increase the levels of awareness among service providers of the unique set of care needs and referral options available to older people with ABI
- e) to increase the levels of awareness among service providers and caregivers of the signs and symptoms associated with ARBI, facilitating the identification of individuals affected by the condition and initiate referrals to appropriate support services
- f) to establish an information platform from which other service providers can develop appropriate service delivery responses to older people among their own service users who are living with complex needs and an ARBI

- g) to broaden the applicability of the Wicking program such that it can be transferred more broadly into mainstream aged care environments
- h) to improve participants' life quality and wellbeing through better access to appropriate care and support and long-term residential aged care that is appropriate, dignified, affordable and culturally relevant.

# 4.2 Project governance

The Wicking project was governed by the Wicking Project Management Committee, which received guidance and advice from the Wicking project Advisory Committee (Figure 10). The principal role of the project advisory committee was to provide the project management committee with guidance, expertise, connections or links with external bodies, and the perspective of distance from day-to-day project activity.

The Operations Group was a subgroup of the Wicking Project Management Committee and met on a monthly basis. The management committee provided regular progress updates to the advisory committee, which met on a quarterly basis to provide continuing input and advice on issues relating to project strategy and development.

The research sub-committee comprised members of the project management and advisory committees. Its role was to provide the Research Manager with guidance on all aspects of research design and methodology, thereby maximising the potential of the project to achieve outcomes that:

- were in alignment with current industry/sector attitudes and directions
- would contribute further to current best practice in the field
- were methodologically robust and complied with current research practice
- were not introspective
- were regarded as credible and valid
- achieved academic/sector/government recognition and acceptance.

Ongoing liaisons with the then Australian Government Department of Health and Ageing (now the Department of Health) and other policy-focused representative bodies has enabled Wintringham to cite the Wicking project as an example of an innovative model of care designed to address the issues of ageing, homelessness and complex needs using a valid and scientifically robust approach. Interest in the development and progress of the Wicking projects has served to progress the project's aim to influence change in policy and funding structure to develop long-term care options for such disadvantaged and marginalised populations.

#### 1. The Wicking Advisory Committee

Wintringham, CEO (Chair)

University of Melbourne, Professor of Psychiatry, Department of Psychiatry Mental Health Council of Australia, Former Chair,

Drug Health Services, Medical Director Addiction Medicine, Western Hospital Clinical Neuropsychologist, Company Director

Elder Rights Advocacy CEO

Managing Director, Applied Aged Care Solutions

Wintringham, Research and Behaviour Support Manager

Wintringham, GMO/DGMO

## 2. Project Management Committee

Wintringham, Research and Behaviour Support Manager (Chair) Wintringham Eunice Seddon Site Manager Clinical Neuropsychologist Wintringham GMO/DGMO Wintringham Wicking Case Manager

> Wintringham Chief Financial Officer

Wintringham Finance Team

Wintringham CEO Guided by Wintringham Board of Directors

# 3. Wicking Operations Group

Wicking Project Manager Wintringham DGMO Wintringham Eunice Seddon Site Manager Wintringham Wicking Case Manager

Research Assistant/Administrative Support

Wicking Project Neuropsychologist
Supervised by
Clinical Neuropsychologist, Company
Director

Wintringham General Manager Operations

DGMO & Operations Support Services

Figure 10 Governance of the Wicking II project

# 4.3 The Wicking II model

The Wicking II project was enabled by the award of a second Major Strategic Initiative Grant by the JO & JR Wicking Trust (The Wicking Trust) administered initially by ANZ Executors & Trustee Company Limited and subsequently by Equity Trustees Limited. The project, titled *The Wicking II Project – An evaluation of a new service model for older people living with alcohol-related brain injury and complex behaviours as they transition into long-term residential aged care*, commenced in June 2012. The principal objective of the project was to consolidate and expand on the findings of the Wicking I project. As with the Wicking I project, Wicking II was orchestrated and implemented by Wintringham Specialist Aged Care, a not-for-profit provider of aged care services to older people who are homeless or at risk of homelessness.

The project received ethical approval by the full panel of the Austin Health Human Ethics Committee (HREC Approved Project No: H2012/04643) and was overseen by highly regarded and esteemed members of an advisory committee representing academia and key service industries (

Appendix A: The Wicking II Project Advisory Committee Members). The evaluation methodology and inventory used in the Wicking I project essentially remained unchanged in the Wicking II project. The Wicking II project evaluation was designed to determine the effectiveness of this program in achieving its aims, by measuring change in psychosocial outcomes for participants (n=24).

The evaluation used both qualitative and quantitative methodologies. Quantitative measures, including neuropsychological assessments, depression and aggression scales, life satisfaction and quality of life assessment tools, determined the effect of transitional change. Assessment measures were collected from all participants at three standardised time points during their participation in the trial: pre-project, inter-project (3 months), end-of-trial (approximately six months). Information gained from these assessments was not doubly blinded, as it was often used in an iterative manner in the care of participants.

The Wicking II model incorporated intensive case management, individualised recreation programs, one-on-one attendant care support, controlled drinking and smoking programs, neuropsychological evaluation and support and individualised behavioural support programs. Rather than creating one overarching psychosocial model of care, the Wicking II model adapted to meet the individual needs of each participant. This in effect meant that the Wicking model of care entailed a vast array of 'care models', all focused on empowering participants, ranging from those that were highly structured and directed, to those that encouraged a high degree of flexibility and autonomy. To achieve this, the Wicking II project recruited a workforce of dedicated employees who shared a positive productive relationship with each other, with key external agencies, and with government and funding bodies, while delivering a comprehensive and innovative structured activity program in a harmonious living environment.

This multidisciplinary specialist team consisted of experienced personnel, all trained to work effectively with older people living with an ARBI. The team consisted of a neuropsychologist, a case manager, a research and behaviour support manager, diversional activity attendants, the residential site manager and a care manager/registered nurse. Additional expertise was co-opted as required from specialty service providers, including drug and alcohol, mental health, medical, guardianship and administration services. Many of these relationships were pre-existing, having been forged through the Wicking I project. This multidisciplinary team was responsible for the successful implementation of the intensive support program (the Wicking program) over its three years of operation. They provided specialist support to the participants and facility staff, with the aim of facilitating the success of enduring tenancy and improving the life quality of project participants.

Fundamental components of the support intervention consisted of case management, neuropsychological assessment and individualised behaviour management planning and monitoring, staff education and training, and one-on-one support from a diversional activity attendant, to facilitate participation in individually designed structured activity programs. The key elements of the Wicking II model included intensive structured activity programs, behaviour modification strategies and individualised drinking and smoking harm minimisation programs.

#### **Identity lost**

An intelligent, witty and warm woman who was frustrated to find herself in the situation of needing aged care. A proud woman who unfortunately lacked insight into her need for

support. Her multiple brain injuries had affected her ability to understand and accept that she needed care and this brought with it restrictions and loss of independence that were inherent with an aged care environment. This often resulted in anger and desperation and sometimes a fierce rage. Rage could be accompanied with threats of harm to self or others and on occasion these threats were acted upon.

G would often assert her perception of social status through criticism of others, both coresidents and staff. Criticism of incorrect grammar, appearance or lifestyle choices were common. Looking to find a raw nerve and evoke a reaction. Perhaps to cause hurt or perhaps to make others feel her pain. Those who would respond in an authoritarian manner or with anger became regular targets for G's rebuttals because she had evoked a reaction from them. Those who were kind, showed empathy and were patient fared much better.

An example of such is when a staff member met G and through general discussion mentioned the area in which she lived. G made a rather negative comment, in a condescending tone, stating that she was surprised the staff member came from the western suburbs. The staff member continued the conversation in a humorous tone by confirming that they did come from the western suburbs and loved where they lived. The staff member stated that even though they came from the west, they could walk and talk and drive, they had schools there too and well educated people. G laughed along and a positive relationship was formed. No rage or threats of harm. Just laughter.

G had lost many of her life roles including being a partner, a mother, a grandmother, an extended family member, a friend and a community member. In her previous life, G cooked, cleaned, went out at will, bought what she wanted, ate what she wanted and socialised with a wide circle of friends. G's role in her family had been dramatically reduced over the years due to health issues, brain injury and resulting complex behaviour. G's choices were now sadly limited.

Distress at the loss of life roles and choices was expressed in a way that challenged others. To acknowledge these losses and show compassion would reduce the incidents of distressing behaviour and enable others to see glimpses of the fabulous woman behind the pain.

#### 4.3.1 Structured activity/recreation programs

The Wicking recreation program was characterised by a process that assisted participants to pursue any desired recreational interest or life choice. Diversional activity staff spent time with each participant establishing a rapport, identifying their interests and determining barriers restricting them from partaking in these interests. The final stage in this process involved the removal of these barriers through inventive and innovative approaches designed not to impact significantly on the enjoyment rewards. Much of the program was focused on outdoor or community-based activities. Wicking program participants were initially reluctant to participate in a structured activity program. However, through a persistent and skilled approach, levels of rapport, engagement and participation slowly improved to a point at which the program became an effective tool in the diversion of participants away from alcohol-seeking activities to more enjoyable, rewarding and sustainable pursuits.

## 4.3.2 Behaviour modification programs

The breadth and complexity of issues presented to staff in the provision of care to this client group was exceptional. Behaviour modification strategies were influenced by issues arising from diminished capacity, memory loss, coexisting mental illnesses, volatility, entrenched self-protective behavioural traits and personality disorders. Coping effectively with behavioural problems required the identification and acknowledgment of each participant's neurocognitive capabilities. A

comprehensive neuropsychological assessment was pivotal to achieving a better understanding of neurological and cognitive strengths and weaknesses. The additional benefit of the neuropsychologist also being an occupational therapist was the inclusion of physical and functional strengths and weaknesses in the development of support programs. The determination of overall risk associated with the unmanaged execution of a particular behaviour had to be balanced with the risk inherent with the intervention. Only interventions that assured options, rights and dignity were introduced. For example, responses to sexually driven behaviours were considered with respect to human rights issues such as privacy, confidentiality and respectably acknowledging the individual's sexuality.

The ABCD approach (Antecedent - Behaviour - Consequence - Discussion) was used in the Wicking program to develop and improve behaviour management plans. This theory focuses on the antecedents or triggers for the behaviour, trying to understand what they are and modifying the environment and interactions accordingly. Accurate description of the behaviour is very important in this process. The description must be detailed, yet concise and written using non-judgemental language. It must portray an unambiguous picture of the behaviour when it occurs and should also identify whether the person themselves finds the behaviour disturbing or distressing. The consequence of behaviour very often influences the future occurrence of the behaviour. If the consequence of a behaviour is not accurately identified or is inappropriately managed, the situation may escalate to more extreme or frequent behaviour, which in may turn trigger other negative behaviour responses.<sup>107,108</sup> Discussion involves a team approach in behaviour management. All aspects of a behaviour are brainstormed and plans developed for future actions to be taken to support the participant and staff to adopt more positive, consistent responses to the behaviour, either when they occur or as a proactive intervention to an identified antecedent. This approach to behaviour management takes into account the 'whole person' (their strengths, weaknesses and individuality) and contributes toward a continuous cycle of improvement.

# 4.3.3 Alcohol and cigarette programs

The provision of alcohol in the form of a controlled drinking program had a significant positive influence on the behavioural manifestations of Wicking program participants. It provided respite from daily hardship resulting from not knowing when and how the next drink or cigarette was to be acquired. How will they get the money? How long will they need to scour the footpaths in order to collect enough discarded cigarette butts? Will they face another day wracked with the symptoms of withdrawal? For many, the introduction of a controlled program presented the first opportunity in a very long while in which the choice to forgo a meal in place of alcohol or cigarettes did not have to be made. The drivers of behaviours such as begging, borrowing or stealing were effectively removed.

Through such initiatives, participants were supported to conduct their lives as they wished, with the proviso that their lifestyle choice did not negatively impact on the lives of others. The result was a highly personalised program that balanced the needs of each participant with the financial resources available, while taking into account the impact and risk to their health and wellbeing through continued addictive behaviour. Encouragement and support was provided to participants to establish the skills and confidence required to contribute to the management of these programs while making best use of the recreation and diversional structured activities. Anecdotally, the most positive aspect of commencing an alcohol and cigarette program (reported by participants) was the

regaining of control over the chaos that addiction had created in their lives. They found the program, and their role in managing it, empowering.

# 4.4 Project evaluation

#### 4.4.1 Participant recruitment

Wicking II project participant referrals were sought from services such as health and community care, emergency and crisis intervention services and government agencies, including The Office of the Public Advocate. Referrals were also sought from major public hospitals and psychiatric services, especially for 'long-stay' patients who met the inclusion criteria. These referrals reflected the population of patients for whom previous attempts of discharge into residential aged care had been unsuccessful due to the presence of an ARBI and the nature or intensity of challenging behaviour they exhibited. Another source of referral was Wintringham residential aged care facilities, seeking additional support to effectively manage the care of existing residents living with an ARBI and highly challenging behaviour.

The Wicking II project participant population consisted of individuals over the age of 50 years who were living with an ARBI and severely affected behaviours. These participants were housed and supported in a Wintringham residential aged care facility in Dandenong, Victoria. Participants were selectively recruited for a history of homelessness, continued drinking and unsuccessful tenancies arising from behaviours associated with their ARBI. Further detail on the selection and inclusion criteria for project participation is shown in Table 5.

Table 5 Inclusion criteria for Wicking II project participants

# Requisites Preferable

- Is aged fifty years or older.
- Is ambulant i.e. relatively active.
- Has a long-term, continuing excessive drinking problem.
- Has been determined by the Aged Care Assessment Service as being eligible for residential aged care.
- Has an alcohol-related brain injury confirmed by way of a neuropsychological assessment.
- Has displayed (confirmed) behaviours of unmet need – e.g. challenging, perseveration, aggression.
- Has a history of homelessness or is at high risk of becoming homeless.
- Does not have a mental health condition (reported or suspected) that would preclude them from living collaboratively in a communal environment.
- Does not have an addiction to drugs other than alcohol and cigarettes.
- Is willing to undergo neuropsychological assessment and regular comprehensive project evaluation assessments.
- Is willing to participate in a six-month (approximate timeframe) residential trial.
- Is aware that their participation would not attract any special payments or monetary rewards.
- Is keen to make the commitment and a concerted effort toward self-determined positive life changes.

- Has a history of unsuccessful or problematic tenancies resulting from behaviours associated with alcohol intoxication.
- Is a resident of Melbourne's metropolitan region.
- Is supported by an administration order.
- Is suspected of having a brain injury.
- Has undergone multiple failed attempts at sobriety/detoxification/rehabilitation.
- Is familiar with the locality of the project site (Dandenong).
- Has appropriate long-term accommodation options available to them on completion of the program.

# 4.5 The Wicking II Project participant demographics

The population of Wicking II project participants (n=15) consisted of older adults with an average age of 60 years (range, 51–68 years). All were actively abusing alcohol at the time of their referral to the project, with an average age for commencement of drinking of 26.5 years (±8 years). The average age at which participants first experienced homelessness was 45.6 years (range, 14–64) with an average life duration of homelessness extending over 14 months (±5 months) with one change of accommodation (range, 1–4) within the previous 12 months. This indicates a generally later-in-life loss of secure housing with minimal transience. Most had experienced intermittent periods of homelessness that extended across several years throughout their lives.

Similar patterns of homelessness were reported in another Melbourne study of the demographic profile of people experiencing homelessness. Johnson and Chamberlain (2009) examined the records of 4,291 homeless participants of mixed ages. They found that of the 43% who were experiencing substance abuse problems, 82% had been homeless for 12 months or longer and 76% had experienced two or more periods of homelessness within the past 12 months. In contrast, only

50% of those who did not have a substance abuse disorder had been homeless for that length of time. 109

Six of the Wicking II project participants were women and nine were men. All participants had a high level of behavioural care needs and moderately high levels of physical health care needs appropriate for referral to residential aged care. Participants were referred to the Wicking II project from four sources (Figure 11) of which community support services were the most common.

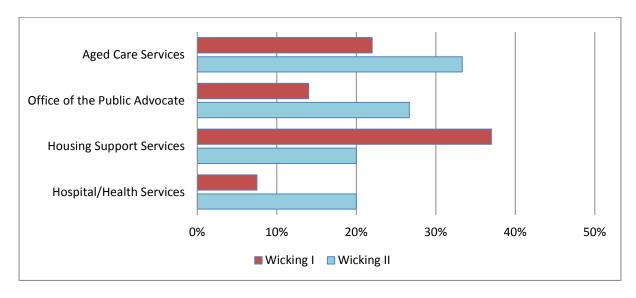


Figure 11 Source of referral for Wicking I and II project participants

Comparisons between the Wicking II and Wicking I participant referral sources reveal that a greater number of Wicking II participants were referred by hospital, aged care and advocacy services and a smaller number by housing support services.

All participants underwent a comprehensive pre-participatory interview from which the following demographic data was obtained. All but one participant was single with the majority being divorced or separated. Almost half of the participants lived alone in public housing, with the remainder having experienced short periods (not exceeding two years) of communal living in a residential aged care environment. One participant lived with his family. The instigation of referrals made by residential age care facilities was their incapacity to provide adequate and continuing support to residents exhibiting extremely complex and challenging behaviours.

Table 6 Demographic data for Wicking II project participants (n=15) and the Wicking I project participants (Wicking and control n=14) prior to their commencement in the Wicking program

	Wicking II		Wicking I	
Participants	n	%	n	%
Gender				
Female	6	40	1	7
Male	9	60	13	93
Age in years, M (SD)	60 (5)		55.9 (6)	
Homelessness				
Age 1st homeless, M (SD)	46 (14)		34.3 (7)	
History of homeless/risk thereof	15	100	14	100
Marital status				
Single	2	13.3	5	36
Married	1	6.7	0	0
Divorced/separated	10	66.7	6	43
Widowed	2	13.3	3	21
Nationality				
ATSI	1	6.7	1	7
Australian (NON ATSI)	12	80	11	79
CALD	2	13.3	2	14

Comparisons between the Wicking II and Wicking I participant demographics shows the larger representation of female participants in the Wicking II Project (Table 7). The average age of all Wicking I participants was younger than that of the Wicking II group and they had first experienced homelessness at a younger age.

Figure 12 shows that the majority of Wicking II participants lived alone or in residential care, had no regular contact with their families and were under administration orders administered by State Trustees (80%). Four participants were also under Guardianship Orders, with a state-appointed advocate guardian through the Office of the Public Advocate. The more notable differences of the Wicking I participant group was that this group was less likely to have lived alone prior to their referral to the project and less likely to have family support or administration orders but more likely to have a guardianship order.

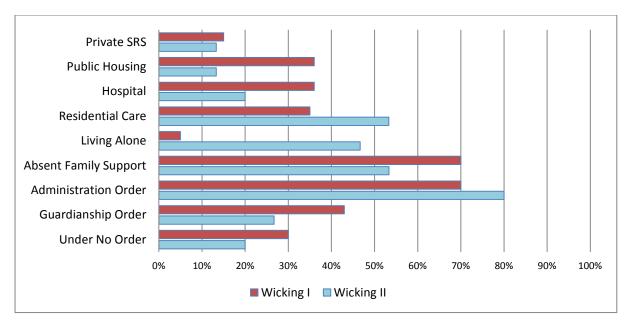


Figure 12 Pre-participatory living arrangements and support networks for Wicking I and II project participants

#### 4.5.1 Education and employment history

The average level of formal education for project participants was between Year 9 and Year 10. This is not dissimilar to the population average for people of a similar age in which more than half (61%) of Australia's older people ( $\geq$  65years) had completed at least Year 10 or equivalent in schooling.<sup>110</sup>

Most of the Wicking II project participants had been regularly employed, drifting in and out of the unskilled labour workforce (Table 7). Most had prematurely ceased work around their mid-forties. These findings are similar for the Wicking I participant group.

Table 7 Pre-participatory education and employment history of the Wicking I and II project participants

Participant Education and Employment	Wicking II		Wicking I	
	n	%	n	%
Years of formal education, M (SD)	10.64 (2.65)		10 (3.03)	
Past employment				
Skilled labour (worked regularly)	2	13.3	2	15
Skilled labour (worked intermittently)	4	26.7	1	6
Unskilled labour (worked regularly)	6	40	4	29
Unskilled labour (worked intermittently)	3	20	6	43

#### 4.5.2 Justice service history

Homeless Law notes that people who are experiencing homelessness, particularly those rough sleeping, are: '(1) more likely to get fines because they are forced to carry out their private lives in public places, and (2) less likely to be able to address the fines through payment or navigating the complex legal system'. <sup>111</sup> In the literature, a number of explanations are commonly used to describe the correlation between homelessness and crime, including that:

• by virtue of living in a public place, people who are homeless are more susceptible to committing public order offences such as trespassing and public urination

- those without stable accommodation (or experiencing financial hardship) may have little choice but to engage in 'survival offending', such as shoplifting and squatting
- substance abuse as a coping mechanism may lead to offending behaviour in order to fund habits
- police may specifically target homeless populations because of perceived community safety issues or because homeless populations are more visible to street policing operations 112
- people who have experienced persistent trauma or who have acquired brain injuries are
  overrepresented in the homeless population and are shown to experience undue contact with
  law enforcement as they may exhibit public behaviours that others find challenging and which
  bring them to the attention of police.<sup>113</sup>

All Wicking II project participants reported receiving a recent criminal charge or conviction. Most resulted from drinking in public or drinking alcohol while travelling on public transport, begging or shoplifting. Nearly all participants had been victims of serious assaults (averaging 4.1 physical assaults each year) and most had regularly been the victim of crime (theft of property or violent assault). Two female participants had been raped on more than one occasion. The majority of the crimes in which participants had been victims were not formally reported to the police (Figure 13). In the absence of advocacy or legal representation, most of these offences or unpaid fines proceeded to court unchallenged, unrepresented or in absentia.

Five project participants had accumulated unpaid infringement notices amounting to thousands of dollars. With little to no material or fiscal assets, these debts were unlikely to ever be repaid. If the person's finances were being managed by an administrator, minimum fortnightly repayment deductions were customarily withdrawn from their pension income, effectively reducing their daily expenditure allowance. In most cases, the ongoing accumulation of fines and the resulting debt far exceeded the amount ever repaid. With less money to live on, let alone sustain an alcohol and tobacco addiction, this process inevitably increased the individual's financial hardship. These stressors were often reported by participants as contributing towards them resorting to shop lifting and petty crime.

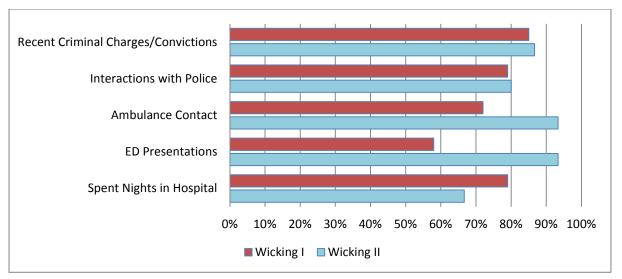


Figure 13 Participant crime and emergency service interactions in the six months prior to beginning the Wicking I and II projects

Compared with the Wicking II participant group, the Wicking I participants had fewer engagements with ambulance services and hospital emergency departments in the six months prior to their participation but surprisingly spent a greater number of nights in a hospital bed.

# 4.5.3 Neuropsychological profiles

At the commencement of the Wicking II project, all but one participant underwent a comprehensive neuropsychological assessment to confirm the presence of an ARBI. The excepted participant was unable to undertake assessment due to a sudden decline in health. For all participants tested, the assessments and subsequent investigations confirmed the presence of significant levels of ARBI.

Premorbid intellectual estimates for participants ranged from average intelligence to borderline impairment (as indicated by scores on the Wechsler Test of Adult Reading). In contrast to premorbid estimates, performance across a range of domains ranged from average to severe impairment. This decline was particularly noticeable in the domains of executive functioning (an individual's ability to organise thoughts and activities and to prioritise tasks as indicated by performance on the Colour Trails task, Verbal Fluency task, and Victoria Stroop Errors score), learning and memory (as indicated Hopkins Verbal Learning Task (HVLT) total score, HVLT delayed score, and scores on Logical Memory 1 and Logical Memory 2), and processing speed (as indicated by Victoria Stroop Dots score) (Figure 14). This pattern of cognitive impairment is consistent with the presence of an ARBI. Due to having English as their second language, two participants' neuropsychological findings were not included in Figure 14. Also, in a few instances, a test or subtest was unable to be administered due to participant refusal.

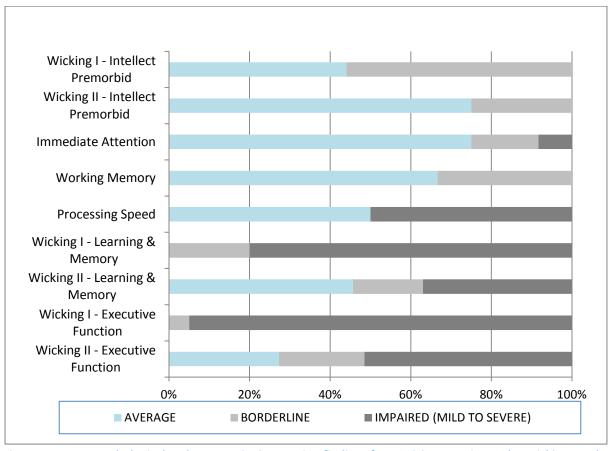


Figure 14 Neuropsychological and community integration findings for participants prior to the Wicking I and II projects

These findings demonstrate that the Wicking I participant group experienced markedly greater levels of cognitive impairment in the measures for which there was comparative data (that is, learning, memory and executive functioning).<sup>37</sup>

#### 4.5.4 Addiction and alcohol abuse

There is considerable debate in the literature as to whether substance abuse precedes or follows homelessness; however, there is consensus that the presence of a substance use disorder typically entrenches people into being homeless as they become marginalised from mainstream institutions. 114,115,116 Not only does the presence of a substance use disorder make it difficult for people to get out of homelessness, it also makes it more difficult for them to remain stably housed.

All of the participants were active heavy drinkers and the majority had experienced multiple failed attempts at sobriety through a number of different support services (Alcoholics Anonymous, rehabilitation and detoxification units). Eleven of the participants had been involved in detoxification programs, often on multiple occasions, over the years leading up to their participation in the project. The average age of commencement of drinking for the participants was 26 years). The average rate of reported alcohol consumption for study participants was 17.1 standard drinks per day with the average content of pure alcohol for a standard drink in Australian being 12.5 milligrams. An average Australian adult consumes around 10 litres of pure alcohol each year, whereas participants in this study consumed approximately 111.15 litres per year, more than ten times the Australian average. 117

The drinking pattern for most of the Wicking project participants involved relatively constant levels of consumption with sporadic binges that fluctuated with access to finances. At times when finances were ample, the upper limit of reported drinking levels included two 3-litre casks of wine or a slab of heavy beer each day. Just over two-thirds of the participants acknowledged that they had a drinking problem (Figure 15). For those who did not acknowledge their problematic drinking behaviour, this misconception could be attributed to the presence of frontal lobe brain injuries associated with the presence of an ARBI which commonly manifests in poor levels of insight. Impaired impulse control and decision-making ability were also contributing to continued patterns of heavy drinking, despite the person acknowledging the consequent detriment and harm incurred.

Two-thirds of the participants smoked daily, with the majority smoking at a rate of approximately 30 cigarettes per day. Nearly all participants acknowledged that the purchase of alcohol and/or cigarettes frequently took precedence over the purchase of food or paying rent or utility bills. This most often lead to rent arrears and an accumulation of debts and fines for participants living in independent housing prior to their commencement in the project. Marijuana was the most commonly used illicit drug for five participants, but for the majority its use peaked in their younger years. For two participants who still used marijuana, its use was infrequent and unreported until later in the study.

Compared with the Wicking I participant group, Wicking II participants demonstrated a greater level of awareness as to the negative repercussions of their drinking behaviour and were less likely to smoke cigarettes. On average, Wicking II participants consumed more alcoholic beverages each day than Wicking I participants (17 standard drinks per day for Wicking II participants versus 13 drinks – see Table 10) and even though there were fewer Wicking II participants who smoked, those who did consumed an average of three more cigarettes each per day. The lower levels of awareness of drinking problems identified by the Wicking I participant group could be explained

by the higher levels of cognitive impairment and, potentially, frontal lobe injury measured. These changes in cognitive functioning have been shown to influence a persons' level of insightfulness and awareness of the consequences of their actions.<sup>37</sup>

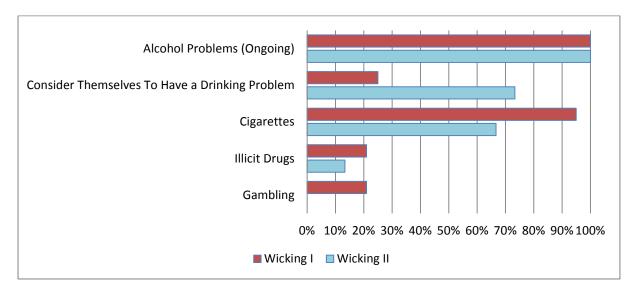


Figure 15 Reported addictive behaviour exhibited by participants prior to the Wicking I and II projects

#### 4.5.5 Challenging behaviour profile

The nature of challenging behaviour exhibited by participants was rarely accurately self-reported. Estimates of frequency data therefore relied on third-party reports from neighbours, service providers, etc. The most frequent categories of behaviour exhibited were verbal aggression, wandering/absconding and socially inappropriate behaviours (Figure 16). These behaviours, in various forms, were reported for all project participants. Examples of verbal aggression included the frequent use of profanities, loud abusive language and threats of harm to neighbours, police, care staff and hospital staff. Examples of socially inappropriate behaviour included being socially awkward, creating a nuisance or annoyance, non-compliant or oppositional behaviour, engagement in petty crime or unlawful behaviour. By far the most common was presenting a danger or risk to self and others, usually while intoxicated. Examples of wandering/absconding included becoming disoriented while intoxicated in the community and failing to return to the accommodation within the specified time.

Physical aggression directed toward objects included breaking windows and doors or throwing furniture or fittings in domestic environments. Physical aggression directed toward other people mostly included pushing or lashing out toward people. Examples of sexually inappropriate behaviour most commonly involved sexually inappropriate comments or insinuations but also included inappropriate touching and gestures.

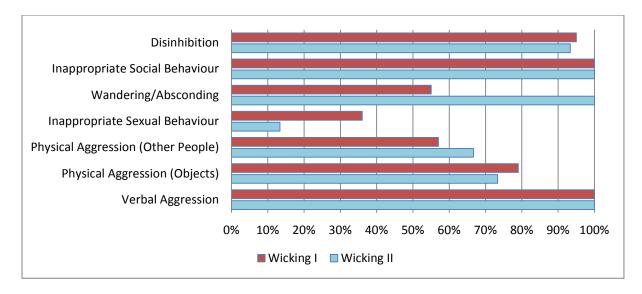


Figure 16 Reported incidence of challenging behaviour exhibited by Wicking I and II project participants prior to commencement

## 4.5.6 Mental health profile

Just over half (53%) of the participants reported recently suffering from a major mental health problem (Figure 17). The prevalence of 12-month mental disorders in the general Australian population varies across age groups, with people in younger age groups experiencing higher rates. Less than 15% of people aged 54–65 years, less than 10% of people aged 64–75 years and 5.9% of those aged 75–85 years had a 12-month mental disorder. As the average range of project participants age fell within the 54–65 category, this places them at three times higher than the national average.  $^{118}$ 

Of those who reported having a major mental health problem, all but one reported anxiety as the major problem. The other individual nominated schizophrenia as their major mental health problem. The remaining participants reported that they either did not have one, or did not know what their major mental health problem was. A third of the participants had attempted suicide or experienced suicidal ideation. The same proportion had carer-rated symptoms of a current appetite/eating disorder (Figure 18).

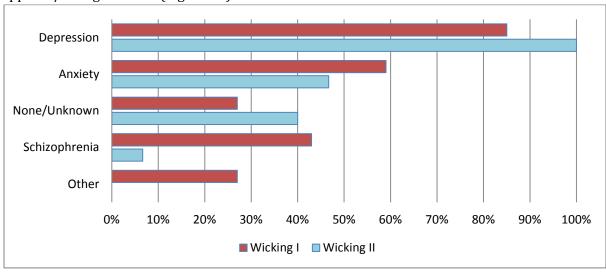


Figure 17 Self-reported major mental health problems among participants prior to the Wicking II project

The rate of mental health problems in the participants is likely to be higher than 53%. Every participant endorsed experiencing low mood. Furthermore, based clinical cut-offs for the Hospital Anxiety and Depression Scale (HADS), Time 1 scores show that two-thirds of the participants showed clinically elevated mood symptoms pre-project, with 1 showing elevated depressive symptoms, 4 showing elevated anxiety symptoms, and 5 showing both elevated depressive and anxiety symptoms (Figure 19).

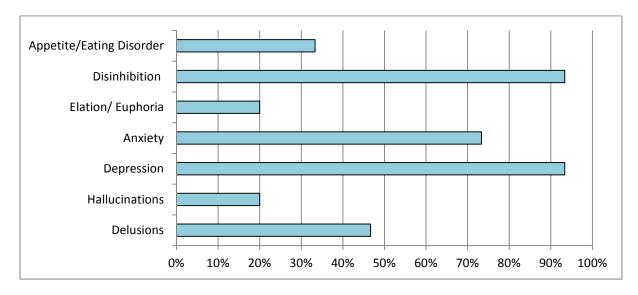


Figure 18 Carer-reported major mental health problems based on the Overt Behaviour Scale among participants prior to the Wicking II project

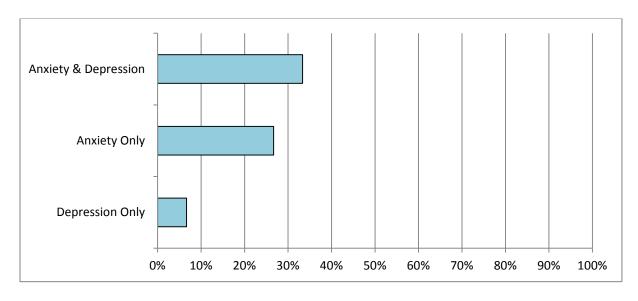


Figure 19 Rates of clinically elevated mood symptoms based on Hospital Anxiety and Depression Scale among participants prior to the Wicking II project

#### 4.5.7 General health profile

Not surprisingly, the health status among Wicking II participants reflected a population of significantly older age (Figure 20). For the majority, primary health care was principally accessed via the public hospital emergency department. The most frequent neurological disorders, aside from ARBI, were traumatic brain injuries (usually acquired in fights and falls) and peripheral neuropathy – more specifically, the formation of primary axonal sensorimotor peripheral polyneuropathy. There is a high risk of this condition among people who have consumed large quantities of alcohol over an extended period.<sup>119</sup>

The second-most prevalent health issue was renal disorder. This can be attributed to high levels of alcohol consumption which can compromise kidney function, particularly in conjunction with established liver disease. Alcohol-related changes have been observed in the structure and function of the kidneys, which impairs the ability to regulate the volume and composition of fluid and electrolytes in the body. Chronic alcoholic patients may experience low blood concentrations of key electrolytes as well as potentially severe alterations in the body's acid-base balance. 120

Gastrointestinal problems were the next most common disorder. Alcohol-induced damage to the mucosal lining of the oesophagus can result in a broad spectrum of acute and chronic diseases, such as acute gastrointestinal bleeding (from lesions in the stomach or small intestine) and diarrhoea. Respiratory disorders usually occurred secondary to long-term smoking. The majority (73%) of participants were active heavy smokers. The most common respiratory disorders were emphysema and chronic open airway disease. Chronic and acute musculoskeletal conditions were very common and frequently associated with multiple fractures and injuries acquired from physical assaults or as a result of falls (usually while intoxicated).

Poor nutritional intake, infectious disease and circulatory issues were the next most common disorders. Functional changes and mucosal damage in the gut disturb the digestion of some nutrients as well as their assimilation into the body, thereby contributing to the malnutrition and weight loss frequently observed in alcoholics. Circulatory disorders or cardiovascular diseases were characterised by hypertension, past cerebrovascular accidents or events and myocardial infarction. Hepatitis was the most common infectious disease within the participant population. Tumour was the least common condition; of these, skin lesions were the most prevalent.

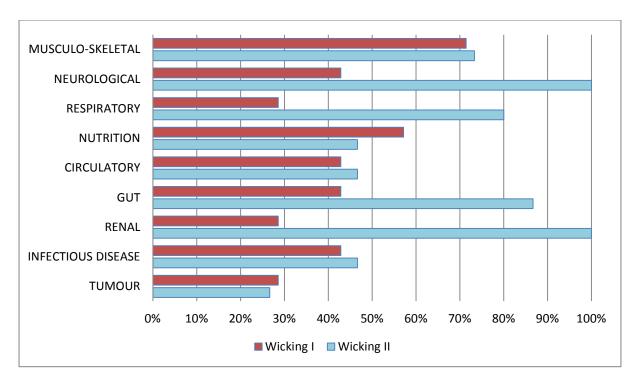


Figure 20 Reported incidence of physical health problems among participants prior to the Wicking I and II projects

19<sup>th</sup> September 2013

#### Dear P

I am writing this to help you when you are feeling agitated or confused.

You are currently living at \*\*\*\*\*\* in \*\*\*\*\*\*\*. You had been in \*\*\*\*\*\* Hospital for many weeks as you had septicaemia and you were quite ill in the intensive care unit. You have improved greatly although you had many seizures which may have affected your short term memory.

My name is \*\*\*\*\*\* and I have known you for six months. I am a case manager at Eunice Seddon Home —Wintringham, where you were living prior to becoming ill. Prior to living at Eunice Seddon, you lived in Wintringham housing in Williamstown and your case manager was \*\*\*\*\*\* has known you for approximately 2 years. \*\*\*\*\* brought you to look at Eunice Seddon Home as you required some extra help regarding your care and health needs. You were pleased with the accommodation and decided to move in.

You have also been receiving extra support through the Wicking research project at Eunice Seddon Home. The Wicking project provides a case manager (me) and carers (below) to support you to reach some personal goals. You have enjoyed many activities and outings with carers including many lunches with \*\*\*\*\*\* at Hot Chilli Indian Restaurant in Dandenong, As well as cooking some of your own meals with your electric wok which has seen many 'hot chillies' in its day!

You have been asking people who visit you about your ex-wife and children. I think you have forgotten that you have not had any contact with your ex-wife or your children for many years. Staff at Eunice Seddon Home have not ever met or had contact with your ex-wife or children.

You had been happy at Eunice Seddon Home for six months and enjoyed your own room and the extra support from carers and nursing staff. Your money is managed by State Trustees and no-one besides you can access it. Your rent to \*\*\*\*\*\*, where you currently live, is automatically paid on your behalf through State Trustees. Your personal spending, which is

managed through State Trustees, will be accumulating in your account and cannot be accessed by anyone other than you.

Staff from Eunice Seddon home have visited you throughout your time in Dandenong Hospital.

\*\*\*\*\* has been the most regular visitor. I have attached some photos below to help you remember some staff from where you lived prior to going to hospital.

The phone number for Eunice Seddon Home is 87922800. This is where you lived prior to becoming ill and being admitted to Dandenong Hospital.

Unfortunately, due to your medical needs, you are not currently able to return to Wintringham, Eunice Seddon Home.

I will keep in touch though. Keep getting better \*\*\*\*\*!

Regards,

\*\*\*\*\*

# 4.6 The Wicking II Project: Staff survey

#### 4.6.1 Working with clients who exhibit complex or challenging behaviour

In general, being aged, homeless and living with an ARBI makes it difficult to find suitable accommodation and specialist support. Staff working with clients who live with an ARBI are often presented with a range of difficulties and challenges that can negatively impact their role and, sometimes, their quality of life. Staff often report violence and aggression as a prominent feature of working with individuals living with an ARBI. High rates of stress and burnout in the sector are often associated with exposure to violence and aggression from clients. As the sector continues to grow and expand, it is important to maintain a level of highly skilled and specialised staff within these services. Considering the difficulties and challenges service providers and staff often face when working with individuals living with an ARBI, it would be beneficial to understand the needs of staff and how to best support them.

Working in an environment where one is exposed to challenging behaviours and violence can elicit a range of negative emotions such as annoyance, fatigue, fear, sadness, disgust, despair, anger and stress. These emotions can lead to work-related strain and burnout. The possible negative consequences of these emotions highlights the importance of effective management and support for staff. Research has indicated that challenging behaviour is one of the most reported work stressors for support staff. Violence towards staff is a frequent occurrence in some health care services; however, prevalence is difficult to determine due to underreporting and inaccurate measuring tools. 126, 127,128,129

Research has shown that the behaviours and characteristics of clients can directly influence how staff work with them. As avoidance may be a response by staff towards clients who have challenging behaviour, it is important for support staff to feel comfortable and confident while working with clients who display challenging behaviours, so that their behaviours do not negatively impact the quality of care they receive. Challenging behaviours can also have indirect consequences beyond the immediate physical impact, such as public ostracisation, avoidance, abuse, exclusion and systematic neglect. 130 It has been implied that individuals with challenging behaviours experience poorer outcomes then those without challenging behaviours. 131

A high incidence of long-term alcohol abuse among residents has lead Wintringham to adapt their model of care to meet the specialised needs of their clients. Wintringham's model of care caters to both residents who have a history of homelessness and those who may have difficulty in securing affordable housing. It delivers a range of services in a non-clinical, non-institutional setting, by providing an environment that encourages independence. A variety of care strategies have been created and gradually refined over the years to successfully deliver appropriate care to residents' special care needs.

A key component of their success derives from understanding the importance of the worker–client relationship and the importance of staff in facilitating and maintaining rapport and building relationships. Staff play a key role in active support and 'a direct link has also been established between the performance of staff and service user quality of life and behaviour in community settings'. Having skilled and motivated staff is important: without them, programs would not be able to provide high-quality specialised care. Direct support staff need specific knowledge, training and skills to work with people with challenging behaviours. With this in mind, staff continue to facilitate the pursuit of treatment options for behaviour concerns and alcohol misuse,

as clients living within Wintringham aged care facilities are not prohibited from drinking in or at the premises.

Wicking II project attendant care workers helped participants achieve individualised goals through one-on-one direct care through the delivery of structured activity programs over 25 hours each week. Staff were rostered on a fortnightly basis to a regular allocation of participants to encourage routine and consistency and continuity of rapport and progress. Maintaining the balance between caregiver burden created by such an intensive support role, dealing with the variability of behavioural manifestations of the brain injury and maintaining positive, effective relationships between staff and participants required constant monitoring and adjustment of rosters.

#### 4.6.2 Staff survey method

As part of the Wicking II project, the experiences and knowledge of staff working with aged clients living with an ARBI were explored. This study comprised a short questionnaire and short interview given to 10 care staff, all staff members from Wintringham's Eunice Seddon Aged Residential Facility in Dandenong, who were in the early stages of employment as an attendant care worker in the Wicking II project. Care staff were invited to participate in the project through an email sent out by the Wintringham research team. The interviewer attended the site and provided staff with information about the project.

Data collection was designed to require only 15–20 minutes per staff member. However, the survey was conducted while staff were at work; therefore, flexibility was needed it had to be able to be undertaken while working without taking too much time away from other tasks. The average duration of participation was around 30 minutes. Administration of the staff survey was approved by the University of Melbourne Human Research Ethics Committee number 1237852 (June 2012) as a minimal risk project and was conducted with the support and approval of Wintringham. Informed consent was obtained from all participants. Care staff were advised they could remain anonymous and that their participation, or not, in this research project would not affect their employment at Wintringham.

The questionnaire was developed using anecdotal evidence gathered from personal experience in the field and from discussions with staff working within the sector and within the organisation (Wintringham). The questionnaire generated information that the researcher was able to further explore in the interviews, shedding light into the experiences and perceived needs of staff. It included questions about demographics, such as age, gender and information about their experience in the field and their education. The second part of the questionnaire asked care staff to rate their level of experience and confidence levels working with clients living with ARBI from 'very' to 'not at all', on a five-point Likert-type scale. Through these data collection methods, the research explored the experiences of staff, identified perceived barriers to conducting their daily work, ascertained their perceived needs and gauged their self-reported existing knowledge of ARBI.

#### 4.6.3 Staff survey results

A profile of the Wicking II care staff who participated in this study is shown in Table 8.

Table 8 Wicking II project support staff demographics

Profile	No of staff					
	Gender					
Male	2					
Female	8					
Age						
18-24 years	1					
25–34 years	4					
35-44 years	2					
45-54 years	2					
55-64 years	1					
Highest qualification						
Certificate	7					
Diploma	2					
Masters	1					
F	Primary qualification					
Nursing	6					
Aged Care	2					
Social Work	2					
	Employment type					
Casual	3					
Part-time	6					
Full-time	1					
Length wor	king in the human service field					
< 3 years	0					
3–5 years	4					
5–10 years	3					
> 10 years	3					
Length of time working with ARBI						
< 6 months	3					
6 months – 1 year	0					
1–3 years	4					
3–5 years	1					
5–10 years	1					
> 10 years	1					

Care staff described facing several challenges in the workplace, particularly around the behaviour they experienced, often daily. The most complex of these challenges were attributed to behaviours associated with the person's brain injury – their impulsivity, aggressive and angry outbursts, moodiness, confusion and withdrawal, particularly in the presence of a coexisting mental illness – leading to violence and verbal and physical abuse. Descriptors used by staff about these behaviours included, 'demanding', 'non-compliant' and 'frustrating'. The continued consumption of alcohol by some residents was reported to compound the challenges for some staff.

A thematic analysis of the interviews revealed a number of major themes related to the experiences and perceived needs of staff working with clients living with RBI. Table 9 summarises the issues and challenges identified by care staff throughout the interviews. The most commonly identified issues include aggression, verbal abuse, manipulation and non-compliance.

Table 9 The Wicking II project care staff training, issues and challenges encountered

Staff	Training in ARBI	Experience in the field	Time working with ARBI	Issues and challenges.
1	No; Experience through job	>10 years	<6 months	Attitudes and expectations, Verbal abuse focused on themselves, Intimidation
2	Yes; Three months provided by Wintringham	3–5 years	1–3 years	Aggression, Bad moods, Called for frivolous things
3	No	1–3 years	<6 months	The way they talk, Their language, Verbal and physical abuse
4	Yes, By Wintringham	3–5 years	3–5 years	Falls, Demanding, Aggression, Depression
5	Yes; In other jobs	3–5 years	1–3 years	Shouting, Demanding
6	Yes; In degree	1–3 years	1–3 years	Verbal abuse, Non- compliance with medication, Manipulation.
7	Yes Some general internal Wintringham training	1–3 years	1–3 years	Their behaviours, Wanting alcohol, Verbal aggression, Physical aggression (throwing things).
8	Yes; In previous jobs	>10 years	<10 years	Verbal and physical aggression.
9	Yes; By Wintringham Wicking project	1–3 years	< 6 months	Frustrating, Non-compliance with alcohol programs, Abuse.
10	Yes; By Wintringham	>10 years	5–10 years	Manipulation, Aggression, Poor reasoning skills.

Outcomes of the qualitative data obtained from the interviews are represented in Figure 21. This shows that care staff mostly felt comfortable and confident working with residents living with an ARBI. All of the care staff rated their confidence in working with residents living with an ARBI as greater than 3 out of 5, with 5 being very confident. One staff member who rated their confidence at a 3 was at the beginning of their employment with Wintringham and expressed that they generally did not feel comfortable or confident in their role. This staff member was also the only one who had not yet had the opportunity to participate in any specific training.

Care staff emphasised the importance of knowledge and experience when working effectively with people who exhibited challenging behaviour. The variety of challenges that care staff identified sheds further light into the complexities that exist among this population and the difficult aspects of working with them. It is worth nothing that some participants were not able to identify the clients who were living with an ARBI and those who had other conditions such as dementia or intellectual disabilities, but they stated that they treated all clients the same in the way they

responded to challenging behaviour. Several also mentioned the importance of being empathic, having a sense of humour and not taking things too seriously as important personal qualities. The most commonly identified perceived needs of staff was ongoing training on improving their understanding of ARBI, developing strategies for managing challenging behaviour, maximising the effectiveness of debriefing, enhancing personal qualities of empathy, maturity, willingness to learn, and having a 'thick skin'. Regardless of the challenges care staff encountered, they all reported they found their job rewarding and enjoyable.

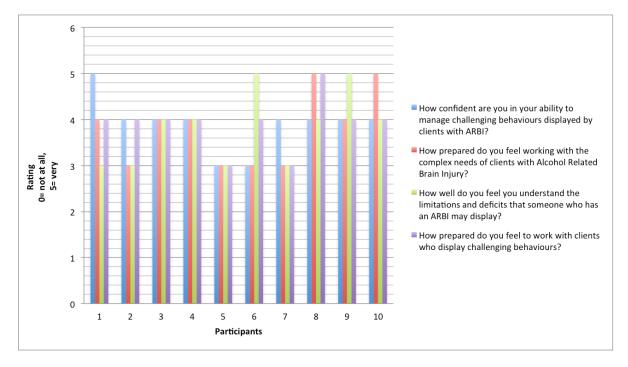


Figure 21 Wicking participant care staff knowledge and confidence in working with people affected by an alcohol-related brain injury

A few staff commented that as they came to know residents better and established a rapport with them, they became more confident and found they could manage their challenging behaviours better. One participant commented that, 'It's not comfortable at all, but you get used to it'. In addition to building rapport with clients, as staff spent more time with participants they were able to build skills and tools based on trial and error. The experience of working with Wicking participants provided staff with skills to working more effectively with individuals living not only with an ARBI but other forms of cognitive impairment or complex behaviour, through the insight gained into each client's individual limitations as well as their strengths.

The importance of debriefing and counselling was commonly highlighted by care staff, with more than half identifying that they and other staff benefitted from counselling and debriefing after major incidents involving verbal or physical abuse and in the event of a death of a resident. Some staff acknowledged that counselling was available within their organisation; however, they found that due to the demands of their role and completing their daily tasks, many failed to seek out counselling and debriefing. Some suggested that debriefing be offered more actively by supervisors for those who may otherwise not seek it. Only one staff member mentioned that they felt that there had not been an incident bad enough to warrant counselling and if there had, they knew how to access it if needed.

Staff also identified a need for continued support from their co-workers and management. They acknowledged how valuable it had been to them during their employment, as most worked one-on-one with participants, isolated from other staff who were often experiencing similar challenges. The opportunity to speak openly about problems or concerns regarding the support of participants acted to validate or normalise issues shared with other staff as well as with their supervisors. One staff member said, 'Everyone is different. We all lean on each other, and each shift has its own issues. In general we all work for the same goal. I don't think that otherwise you could do it'. This shows the importance of informal supports and having co-workers and management who understand and are empathic about the often difficult nature of the work. Research into the importance of informal relationships and perceptions of organisational support confirm these findings by showing that they offer a powerful way to both directly and indirectly combat the negative effects of certain types of role stressors upon worker outcomes. 133

All of the staff who participated in this study reported that they felt, at minimum, somewhat confident in their ability to manage challenging behaviours and that they had a reasonable understanding of the common limitations and deficits experienced by a person living with an ARBI. This was due to a variety of factors, some stating that responding to care needs was instinctive or personality-driven ('If our approach is good, [the client's response is] also good'), life experience ('I think it's your approach and life experience') or training and professional experience in this role and in other jobs. All care staff experienced challenges in their role. Not all staff experienced the same challenges, nor did all define challenging behaviour in the same way. Each individual had developed different coping strategies in order to effectively work with these clients. Their ability to cope and their effectiveness, or confidence in managing challenging behaviours, shaped the way they defined challenging behaviours.

Many comments provided by staff reflected the enjoyment they received from their jobs and that they found their work to be rewarding and satisfying. The interviews revealed that all of the participating staff found their jobs to be rewarding. Furthermore, many discussed the intrinsic and extrinsic rewards they received from their job ('Yeah! Love it'). Many attributed this to the relationships that they had built with the clients, 'I feel very happy to work amongst these type of people'. Work rewards were derived from what would be seen by many as small achievements, such as a smile or a comment received from a client, 'Some things [the clients] say ... they're just beautiful – even when they are abusing the shit out of you'. Many found satisfaction in witnessing the positive progress made by participants in the Wicking program, 'When you see little achievements happen, it's a big difference to them'.

The building of friendships and having a laugh with clients and co-workers was commonly associated with participants' job satisfaction, 'Yeah, I love it ... just the interaction with the residents and the staff as well. I get on well with most of them. One commented that she felt missed when she returned after being away, 'When you go on holidays and you come back, they say 'I haven't seen you in ages'. You feel missed.'

One staff member identified the personal and professional gains that they had achieved from the role, 'The [Wicking] program is so interesting and so beneficial. It helps you to understand more about the [brain] injury itself'. One staff member commented that the skills she used at work are transferrable to dealing with challenges outside work, '… makes it easier to cope with people in the outside world. I learned skills from working with challenging behaviours'.

The length of time working and having experience with individuals living with an ARBI appeared to have little effect on how prepared, confident or comfortable staff felt when working with Wicking II project participants. One staff member who was new to Wintringham rated her confidence and preparedness a little lower than the rest of the participants; however, she was still somewhat confident in her abilities.

Educational background was also not related to how confident, comfortable or prepared staff felt to work with individuals living with an ARBI. Rather, factors such as life experience, training, experience in the industry and a willingness to learn did result in more confidence, comfort and preparedness.

Despite many staff being frequently exposed to challenging behaviour exhibited by clients, in particular verbal and physical aggression, participants appeared to be coping well in their roles by adopting their own techniques for managing the behaviour and minimising the negative effects. Exposure to complex, challenging behaviour is inevitable when working with people living with an ARBI; however, there are interventions that can support staff in dealing with these challenges and provide strategies to reduce the severity and frequency of these behaviours.

These outcomes highlight the importance of continued training for staff on behaviour management practices and strategies on how to implement new skills and frameworks into their daily practice. Furthermore, the importance of regular supervision and proactive debriefing, particularly after the occurrence of a major incident, were highlighted. The results of this study can be extended to other services working with people exhibiting challenging behaviour, regardless of the underlying neurocognitive or mental health disorder.

One study investigated the impact of training aimed at improving staff skills in the preventative and reactive management of severely challenging behaviours in individuals living with mental retardation in residential aged care. The results demonstrated that the training reduced the number of behavioural incidents for most residents. The rates of major reactive strategy use (restraint and emergency medication) also declined over time, as did rates of staff and resident injury. Although only a limited number of these changes showed statistically significant correlations with time, clinical significance was noted when viewed against the complexity of the client group under study. 134

## Consoling self

A highly educated, professional gentleman. Great wit. A bit of a larrikin. Fractured family at the end of their tether. Broken promises – to change, try harder, never drink again.

So many plans. Returning to sailing, joining professional associations, returning to work. Unable to enact the steps required to follow any of them through. Multiple health issues would delay this further 'When I am well. Yes, when I am well.' There was always grog to ease the disappointment.

Scathing , hurtful comments made to others. To inform them he was an educated man. To console himself of his loss.

# 4.7 Results of the Wicking II data analyses

Three data-sets were established from the Wicking II project outcome data: outcomes of clinically validated measures, behaviour frequency observations and frequency data for economic modelling.

Data for the clinically validated measures were collected at two time points. The first of these was pre-project, within two weeks leading up to a participant's commencement in the project. The second was within the final two weeks of a participant's participation in the project. The mean number of months that participants were engaged in the Wicking II project was 11.2 months (SD=5.2, n=15). Pre-project data for the clinically validated measures were collected for all participants. Data was collected from all but three participants at the end of their involvement. These three participants were not assessed due to participant death or terminal illness.

The frequency of challenging behaviour was analysed from behaviour frequency observations, incident reports and staff feedback reports collected quarterly. Time 1 represented the first 3 months (or part thereof) in the program. Times 2–4 represent subsequent three-month periods.

The normality of variables was assessed visually and using statistical tests (Ghasemi and Zahediasl, 2012). The majority of variables were deemed visually and found statistically to meet the assumption of normality. For the variables that were found statistically to not meet the assumption of normality, examination of regression diagnostics indicated that assumptions were not obviously violated.

### 4.7.1 Clinically validated measures

The R-version 3.2.2 for Windows was used to analyse the study data.  $^{136}$  Multiple dependent t-tests were performed and effect sizes calculated to assess differences in scores on clinically validated measures from Time 1 to Time 2 (Table 10).

A Bonferroni correction was performed due to the use of multiple comparisons and the significance level of  $\alpha$  adjusted to  $.0026.^{137}$  Differences of .0033 were considered as potentially showing a meaningful trend. As these differences do not reach statistical significance, however, caution is warranted in their interpretation. Cohen's <math>d effect sizes were also calculated and interpreted with respect to Cohen's conventions (small d = 0.3, medium d = 0.5, and large d = 0.8).  $^{138}$  A small number of additional exploratory analyses were conducted with  $\alpha$  set at .05.

Table 10 Summary of analyses for clinically validated measures comparing Wicking I and Wicking II projects

Measures	Wi	Wicking II project		Wicking I project		
	Time 1 M (SD)	Time 2 M (SD)	р	Time 1 M (SD)	Time 2 M (SD)	р
No. life roles	2 (1.3)	1.9 (1.6)	.79	1.25 (1.2)	2.75 (1.7)	.68
Life satisfaction	13.7 (7.1)	17.4 (7.4)	.093	11.8 (6.4)	15.5 (7.1)	.12
CIQ-Overall	6.3 (3.4)	10 (5.9)	.047*	5.8 (4.1)	9.8 (6.4)	.07
HADS-Anxiety	8.4 (4.5)	5.7 (3.8)	.026*	13.7(3.5)	9.8 (3.5)	.04*
HADS-Depression	6.3 (4.5)	5.4 (4.8)	.52	13.0 (4.5)	5.3 (2.7)	.002*
NPI-Severity	15.5 (3.4)	9.2 (5.5)	.009*	22.0 (5.4)	7.5 (5.5)	0.03*
OBS-Level	14.6 (3.2)	7.7 (4)	<.001*	10.5 (2.1)	6.1 (3.7)	<.001*
AUDIT-Total	27.5 (6.9)	19.8 (10)	.036*	25.3 (5.5)	15.3 (7.5)	.03*
HoNOS-Total	29.3 (5.6)	16.1 (7.5)	< .001*	32.9 (5.4)	13.1 (5.5)	< .01*
No. of drinks	17 (7.7)	5.5 (3.5)	.001*	13 (6)	6.25 (5.5)	< .01*
No. of cigarettes	14.4 (1.8)	11.9 (4.5)	.23	29 (3.8)	12 (2.5)	0.10

<sup>\*</sup>Statistically significant

#### 4.7.2 Life roles

A primary outcome measure for this study was life role participation as measured by the Life Role Questionnaire. Life roles are activities in which people engage that instil a strong sense of purpose, fulfilment and reward. A modified version of the role checklist was used, detailing 10 common life roles (student, worker, volunteer, caregiver, home maintainer, friend, family member, religious participant, hobbyist and participant in organisations) and a category of 'other'. Total scores ranged from 0 to 11, with a higher score indicating higher number of roles participated in. Role participation is enhanced by supporting the development of social relationships and networks, as well as increasing the individual's level of independence in activities that underpin role performance. Light

Typically, an average person of similar age and of non-disadvantaged status would identify with approximately 5 to 6.5 life roles. <sup>140</sup> Wicking II project participants had, on average, only 2 life roles at the start of the project, with the most commonly listed role being a friend. The most commonly cited friends, however, often consisted of drinking buddies and although a number of participants identified themselves as being a family member, many had not been in contact with their family for several years.

The average number of life roles reported among Wicking II participants was not significantly different at Time 2, at 1.9 life roles (t(11) = 0.266, p = .79, d = 0.06). The associated effect size was trivial. The absence of a significant increase in reported life roles may be explained by the recruitment model for the study: participants may have been particularly socially isolated over extended periods prior to their recruitment and therefore may have required more time to develop or re-establish additional life roles.

For the Wicking I project participants, the total average number of life roles increased from 1.25 roles at the outset of the trial to 2.75 roles at its conclusion (Table 10). There are clearly group differences between the Wicking I and Wicking II participants in that Wicking I participants identified a relatively lower number of roles at the outset of their participation. These differences may result from the Wicking I participants experiencing greater need through their experiences of

psychosocial and housing crises immediately prior to their recruitment, whereas the Wicking II participant group may have received better support during this time, thereby averting or reducing the severity of these crises.

### 4.7.2.1 Satisfaction with life

The Satisfaction with Life Scale (SWLS) measure was designed to assess an individual's global judgement of their life satisfaction, by allowing the respondent to weight the importance of life domains in accordance with his or her own values. Higher scores indicate greater levels of life satisfaction with a maximum score of 35. An average SWLS score within a non-disadvantaged aged population is approximately 26.186 Wicking II participants showed a lower than average satisfaction with life (Figure 22). Only one participant exceeded the above proposed average score of 26.

Although not statistically significant, the observed medium effect size suggests that the 22% (4 score points) greater SWLS score for participants might hold clinical importance. Increased sampling may well lead to statistical significance with this measure. Similarly life satisfaction for the Wicking I participant group also increased by 25% (4 score points) over the trial period.

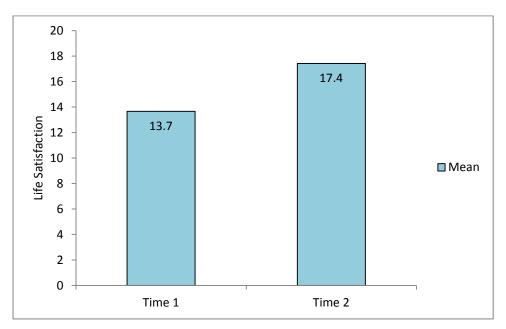


Figure 22 Changes in life satisfaction over time for the Wicking model participants (t(11) = -1.840, p = .093, d = 0.52)

### 4.7.2.2 Community integration

An important objective of a psychosocial program such as that provided by the Wicking II model is to maximise a participant's level of reintegration into the community. However, the cognitive, emotional, psychosocial and physical impairments associated with ARBI can limit an individual's ability to return to work, social activity, home tasks, recreation and other productive endeavours. Individuals from impoverished backgrounds often face difficulty returning to productivity and normalcy.

In the Wicking II project, the Community Integration Questionnaire was used to assess this variable. It provides accurate measurement of key concepts that define community integration, which are integral to brain injury rehabilitation. 141 Figure 23 shows a trend toward increased

community integration from pre-project to the end of the participants' involvement in the project. This trend was associated with a medium to large effect size, suggesting its clinical relevance.

Increases in community integration were facilitated through interventions such as compensatory strategies, role modelling, retraining and coaching. One of the key successes of the intervention lay in the belief that everyone, regardless of disability, is capable of being a useful and productive member of the community when provided with the right type, level and intensity of support. The model established a home environment in which participants' skills and presence were valued and their limitations were accommodated.

Similarly, the Community Integration Questionnaire findings for the Wicking I participants did not demonstrate statistically significant change over time; however, a modest increase was measured in levels of integration indicated by the productivity subscale of the CIQ.

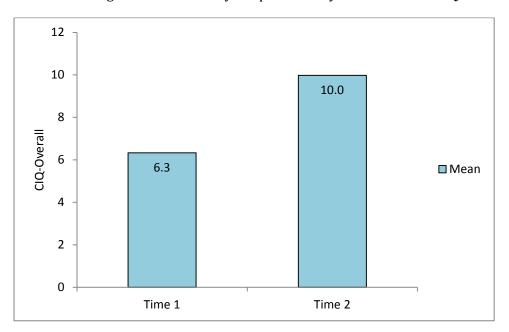


Figure 23 The Community Integration Questionnaire total score (t(11) = -2.237, p = .047, d = 0.76)

## 4.7.2.3 Anxiety

A maximum score for both anxiety and depression as measured on the Hospital Anxiety and Depression Scale (HADS) is 21.183,184 Scores below 7 for both anxiety and depression are considered within the normal range. Scores of 8–10 indicate a mild severity disorder; scores of 11–14 indicate moderate severity and scores of 15–21 are a probable indicator of clinical pathology requiring further assessment.

Figure 24 shows a trend of decreased anxiety scores for Wicking II participants associated with a medium to large effect size. Pre-project, average anxiety scores lay in the mild severity range at 8.4. Of the participants, 5 had scores in the normal range, with 4 in the mild range, 2 in the moderate range and 1 in the severe range. Prior to leaving the project, average anxiety scores had decreased 32% into the normal range at 5.7. At this time, 9 participants had scores in the normal range, with 2 in the mild range and 1 in the moderate range. Decreased anxiety was likely to be influenced by three key factors: the attainment of stable, secure housing; access to comprehensive health care; and being relieved of the, at times, all-consuming quest to acquire alcohol.

The average anxiety scores for Wicking I participants dropped by 28% over the trial period; however, anxiety levels at the commencement of participation were markedly higher (HADS 13.7) than that of the Wicking II participant group (HADS 8.4). At the exit point of the trial, average anxiety scores for Wicking I participants (HADS 9.8) were higher than the average entrance scores of Wicking II participants (HADS 8.4). These differences once again indicate that Wicking I project participants were experiencing higher levels of anxiety due to anarchic experiences in the period leading up to their commencement of the project.

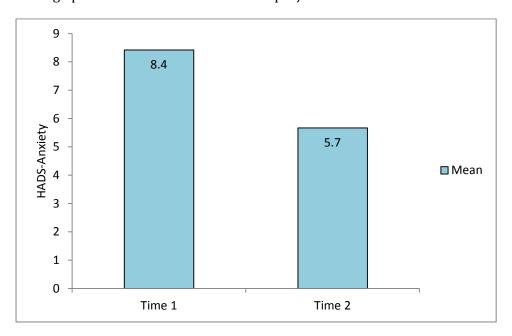


Figure 24 Hospital Anxiety and Depression Scale (HADS) – Anxiety assessment (t(11) = 2.561, p = .026, d = 0.66)

## 4.7.2.4 Depression

No statistically significant change was found in levels of depression for participants over time (Figure 25). The observed effect size was trivial to small. Although hypothesis testing and effect size analysis did not point toward a trend of decreased anxiety, overall, participants dropped in depression classification severity. Pre-project, 8 participants had scores in the normal range, with 1 in the mild range and 3 in the moderate range. At the end of their time in the project, 9 had scores in the normal range, with 2 in the mild range and 1 in the moderate range.

In contrast to the trend of decreased anxiety for the participants, the relative stability of these low levels of depressive symptoms might be explained by the unexpectedly low pre-project levels of depressive symptoms within the group. Wicking II participants experienced lower levels of depression (HADS 6.3) than Wicking I participants (HADS 13), but the average scores at the conclusion of their participation were 5.4 and 5.3, respectively. Once again this reflects a higher prevalence of anxiety and depressive disorders among the Wicking I participant group prior to their participation in the project. These group differences are postulated to be derive from variations in recruitment protocols.

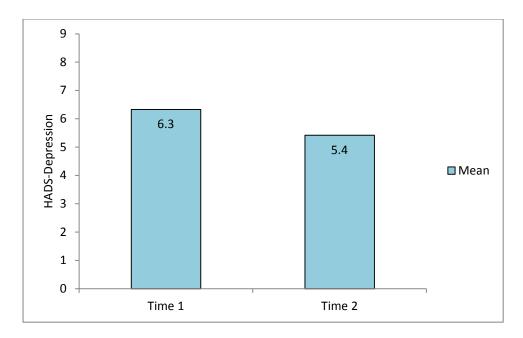


Figure 25 Wicking II project participant Hospital Anxiety and Depression Scale – Depression assessment (t(11) = 0.670, p = .52, d = 0.20)

## 4.7.2.5 Neuropsychiatric behaviour

The Neuropsychiatric Inventory Questionnaire (NPI) assesses non-cognitive psychiatric features and behavioural disturbance (elation/euphoria; apathy/indifference; disinhibition; irritability/liability; motor disturbance; night-time behaviours; appetite/eating). Higher scores indicate greater severity in neuropsychiatric behavioural disturbances. Approximately 90% of regular aged care clients rate NPI scores of 15 or less. 142

A strong trend towards a decrease in neuropsychiatric symptoms was found (Figure 26). NPI-severity scores decreased (41%) from 15.5 at Time 1, to 9.2 at Time 2. The large magnitude effect size associated with this finding demonstrates the real-world potential clinical importance of this change. Increased sampling would likely lead to statistically significant results.

The Wicking I project findings yielded an overall significant decline in scores over time for participants whose average score prior to the commencement of the program was 22 (in the most severe classification range); however, by the end of the trial, their average score dropped some 66% to 7.5, placing this group within the mild classification range. Notably, the Wicking I participant group displayed much higher neuropsychiatric behaviour scores at the commencement of the trial when compared with the Wicking II participants. This indicates that, as a group, the Wicking I participants displayed a greater number of more severe behaviours prior to the program. Once again, this may be attributed to the greater levels of personal and housing stress that this group was experiencing prior to their referral to the project.

## Man behind the facade

Fellow residents and staff had been building negative attributions toward him. His reputation of being rude, aggressive, uncooperative, and sexually inappropriate was growing. He often threatened graphically detailed violent acts toward himself and others. More storytelling than anything sinister. Seeking a reaction, evoking a response, interaction, good or bad – better than nothing. Bored.

Responded well to requests for respectful interactions. Responded well in general to someone taking the time to listen. Being told that he was a gentleman. He resisted initially but eventually accepted that he was a likeable person and was liked.

After witnessing positive engagements between him and staff and other residents, negative attitudes lessened. More social time for him. More listening. More talking. More respect all round

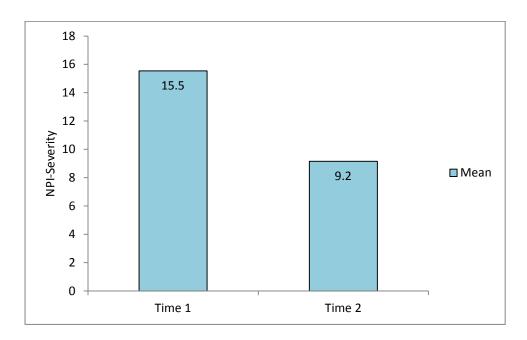


Figure 26 Wicking II project participant changes in neuropsychiatric behaviour severity over time (t(12) = 3.130, p = .009, d = 1.40)

#### 4.7.2.6 Overt behaviour

The Overt Behaviour Scale (OBS) was used to measure changes in challenging behaviour. This validated instrument quantifies the frequency and severity of a range of challenging behaviours, including verbal aggression, physical aggression against objects, physical aggression against self, physical aggression against other people, inappropriate sexual behaviour, perseveration or repetitive behaviour, absconding, inappropriate social behaviour and lack of initiation. Higher scores to a maximum of 34 indicate a greater level of behavioural disturbances. The OBS was selected over other measures of challenging behaviour because of its suitability for use in a community setting with a range of disability groups and because it covers a broad spectrum of challenging behaviours. 143

Figure 27 demonstrates a significant decrease in level of challenging behaviours that was associated with a large magnitude effect size. The level of behavioural disturbance among Wicking II participants dropped approximately 47% from Time 1 to Time 2. Based on the statistical testing

and effect size calculations, a clinically evident reduction in challenging behaviour was apparent from pre-project to the end of the participants' involvement in the study.

In the Wicking I project, there was a similar reduction in participant scores on the OBS (approximately 48%, with scores dropping from 10.5 to 6.1) after an initial rise in scores after three months of participation. This initial rise in behaviour scores was not apparent in the Wicking II participants, indicating that they did not have increases in challenging behaviour during the initial settling down period. Surprisingly, the scores on the NPI behaviour assessment for the Wicking I participant group were higher than the Wicking II participants but the scores on the OBS for the Wicking I participant group were lower, particularly at the outset of their participation.

The OBS has a stronger focus on aggressive, sexual and repetitive behaviours, whereas the NPI is more focused on psychiatric symptoms, agitation and mood disorders. These group differences may therefore reflect differences in the incidence of mental illness between the groups – just over half (53%) of the Wicking II participants reported that they had recently experienced a major mental health problem, whereas more than 70% of Wicking I participants had reported such mental health problems.

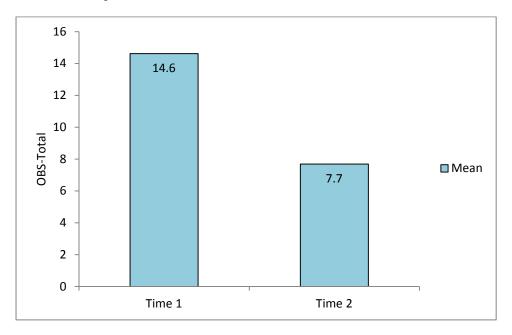


Figure 27 Wicking II project participant changes in the total level of overt behaviour (t(12) = 4.683, p = < .001, d = 1.92)

### 4.7.2.7 Alcohol use disorder

The Alcohol Use Disorders Identification Test (AUDIT) screening assessment tool is a questionnaire developed by the World Health Organization to evaluate a person's use of alcohol. Classification of drinking behaviour shows low-risk scores rating 0 to 7, risky or hazardous drinking rating 8 to 15 and a high risk of eventual harm indicated by scores ranging from 16 to 19. Scores of 20 or greater (maximum score = 40) indicate a definite risk of harm and almost certainly indicates alcohol dependency.<sup>144</sup>

Figure 28 shows a trend toward lower-risk drinking behaviour in Wicking II participants that was associated with a large effect size. Not surprisingly, pre-project, all participants scored within the high risk or definite risk categories. There was a 28% (7 point) decrease in average AUDIT scores

from pre-project to Time 2. Although not statistically significant, the observed large effect size suggests that this trend toward lower risk drinking behaviour may be important and of clinical significance. Similarly, the Wicking I project participants also experienced a large decrease of 40% (10 points) in scores from pre-project to Time 2.

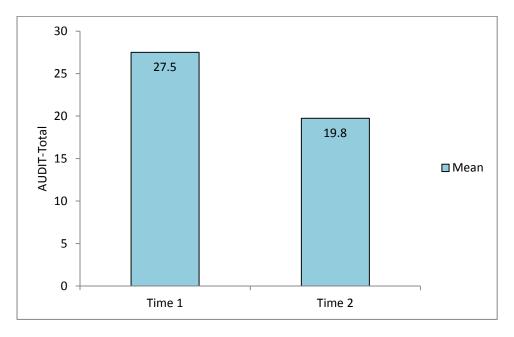


Figure 28 Alcohol Use Disorders Identification Test (AUDIT) for Wicking II participants (t(11) = 2.383, p = .036, d = 0.90)

## 4.7.2.8 Alcohol consumption

The average daily alcohol consumption of Wicking II participants was calculated by determining the number of standard drinks contained in the quantity of specific beverages consumed. Preproject estimates of drinking patterns of Wicking II participants showed an average daily intake of seventeen standard drinks per day (M=17.1, SD=10.2) plus additional binges. Binges occurred at an average frequency of once per week. As with the Wicking I participants, the volume of alcohol consumed during binges was generally excessive (e.g. an entire slab of beer or a two-litre cask of wine consumed within one to two hours). Previous research indicates that alcohol-related social problems are associated with the volume of alcohol consumed and the frequency of binge drinking.  $^{145,146}$ 

The National Drug Strategy Household Survey defines risk of harm in the short term (e.g. motor vehicle accidents, falls) as at least one episode of alcohol consumption per week of 7 standard drinks or more for males, and 5 standard drinks or more for females. There were declines in the proportion of people aged under the age of 40 years who were drinking at risky levels between 2010 and 2013 but there were no significant differences in the proportion of people aged 40 years or older drinking alcohol at risky levels in 2013 – from 2001 to 2013, there was little change in risky alcohol use among this group. The age group most likely to drink daily has been shown to be those aged 70 years or older, for both males (21%) and females (10.0%). A snapshot of alcohol consumption in Australia demonstrates (Table 11) that the Wicking II participants were by far a minority group within the population of ageing Australians with respect to risky drinking. All participants exceeded drinking levels that placed them at significant risk of long-term harm.

Table 11 Percentage of older Australians at various levels of risk of long-term harm through the consumption of alcohol, 2013 (%)

Age group	Abstinent	Low risk	Moderate risk (weekly)	High risk (daily)
40–49	15.8	39.9	11.4	6.3
50-59	17.0	48.2	8.0	6.2
60-69	21.2	56.1	4.1	5.7
70+	32.7	58.0	1.4	2.8

The Wicking II participants showed a significant reduction in their drinking levels (Figure 29). The 66% decrease in average alcohol consumption can, for the most part, be attributed to an effectively administered controlled drinking program. Other factors, however, such as improved health, a reduction in mood symptoms and an enhanced role in community participation were also thought to have contributed. The large magnitude effect size points towards the clinical importance of the decrease in drinking levels, and is consistent with the trend toward lower-risk drinking behaviour as indicated by AUDIT-Total scores.

The Wicking II project participants drank, on average, two standard drinks per day more than the Wicking I participant group on their commencement of the program. Despite this, the Wicking I participants also experienced a significant yet smaller (40%) reduction in drinking levels, from just over 13 drinks per day at the outset to a little over 6 drinks at Time 2.

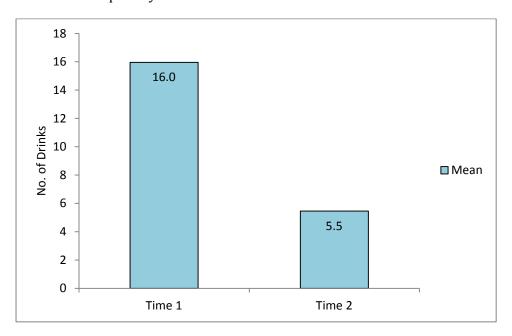


Figure 29 The number of standard drinks consumed by Wicking II project participants per day (t(12) = 4.237, p = .001, d = 1.75)

## 4.7.2.9 Cigarette consumption

Two-thirds of the Wicking II participants smoked cigarettes. Data for two participants was excluded from this analysis as the post-project data was unavailable. The average number of cigarettes smoked per day pre-project was just lower than that reported for an average older Australian adult (participants smoked 14.4 cigarettes per day). At the end of the project, participants smoked on average 11.9 cigarettes per day. Analyses did not identify a statistically

significant change in smoking levels for Wicking II participants (Figure 30). The observed effect size was, however, of medium to large magnitude.

Daily smoking among the general Australian population declined between 2010 and 2013 and has almost halved since 1991 (from 24.3% in 1991 down to 12.8% in 2013); however, over the same period, there was little change in the daily smoking rate among people aged 50 years and older. In 2013, the Australian population (aged 14 years+) smoked an average of 96 cigarettes per week. These figures, however are distorted by higher smoking levels in older age groups; for example, it is known that smokers aged 50–59 smoke an average of 125 cigarettes per week. This trend applies to males and females. Is

Table 12 Tobacco smoking intensity, people aged 50 years or older, by age, 2010 to 2013 (%)

Age group	Males daily smoker	Females daily smoker	Persons heavy smoker
50–59	16.7	13.4	44.1
60–69	12.9	10.3	44.3
70+	6.6	5.2	40.4

Research has shown a close association between individuals who smoke tobacco and those who consume alcohol at harmful levels. <sup>152</sup> This study reported that the amount of tobacco smoked was associated with the amount of alcohol consumed and the severity of alcohol dependence, with a correlation between the severity of alcohol and nicotine dependencies. <sup>153</sup>

The findings of the Wicking I project demonstrated a significant decrease in cigarette smoking between Time 1 and Time 2. In contrast, a lower proportion of Wicking II participants smoked. Those who did smoke smoked fewer cigarettes pre-project than their Wicking I project counterparts. In Wicking I, a reduction in smoking was attributed to the controlled cigarette administration program, as well as increased psychosocial wellbeing. Changes in societal attitudes and negative attributions toward smoking, legislative changes leading to an increased cost of cigarettes taxes and the ban on smoking in public spaces may have influenced the decreased average levels of cigarette consumption for participants in the time between the Wicking I and Wicking II projects.

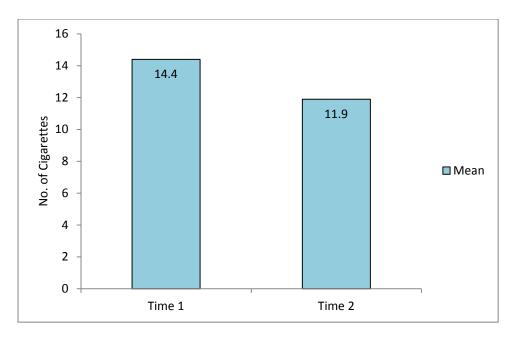


Figure 30 Number of cigarettes smoked by Wicking II participants per day (t(7) = 1.330, p = 0.23, d = 0.73)

### 4.7.2.10 Health of the nation outcome scales

Health of the Nation Outcome Scales (HoNOS) provide measures of psychosocial functioning through a concise assessment of the severity of a range of health and social problems likely to be experienced by people with various neurocognitive disorders. There are several versions of the measure, but the HoNOS-ABI (for acquired brain injury) was selected as the most appropriate for Wicking I and II project participants. <sup>196</sup> The HoNOS measures scores out of a total of 48 and consists of 12 scales including agitation, depression, cognitive and physical problems. Each scale is scored from 0 (no problem) to 4 (severe to very severe problem). In a study that investigated the HoNOS scores of patients attending a regional Australian mental health service in Illawarra, the mean total scores were 13.4 for inpatients, 12.3 for residential clients and 9.7 for ambulatory clients. <sup>154</sup> These findings indicate that with an average score of 29.31 at Time 1, the Wicking II participants presented with extremely high levels of psychosocial problems.

Figure 31 demonstrates that a statistically significant decrease in average total HoNOS-ABI score was measured between Time 1 and Time 2 for Wicking II participants. The decrease was associated with a large magnitude effect size, constituting a 45% reduction in scores. The statistically significant result and large observed effect size suggest this change was quite evident clinically.

Similarly, Wicking I project participants also showed significant levels of improvement in average HoNOS-ABI total scores over time, with a 57% reduction. This indicates that the HoNOS-ABI is a sensitive tool in measuring change over a course of psychosocial intervention for participants of the Wicking project. The tool was developed as an outcome measure targeting psychiatric and other sequelae of brain injury. <sup>155</sup> The psychiatric and psychological consequences of brain injuries, particularly when combined with cognitive impairments, may significantly contribute toward the obstacles presented to people within this population as they attempt to gain and sustain independent housing and engagement with appropriate care and support services.

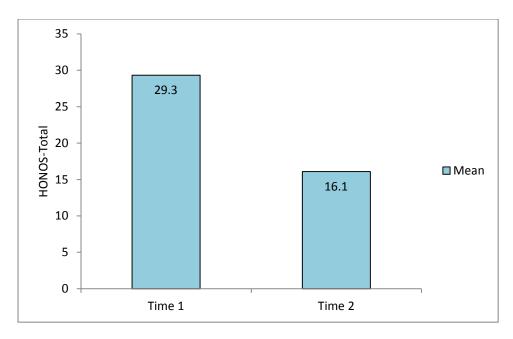


Figure 31 Wicking II Participant Changes in Health of the Nation Outcome Scales (HoNOS-ABI) (t(12) = 6.049, p < .001, d = 2.00)

## 4.7.3 Other wellbeing measures

## 4.7.3.1 Physical health

Figure 32 demonstrates the frequency of diagnoses in the Wicking II participants at Time 1 and Time 2. All participants had neurological and renal diagnoses; most also had gastrointestinal, respiratory and musculoskeletal diagnoses. The frequency of diagnoses remained the same across time for all diagnoses, apart from nutrition and infectious disease. The diagnosis of nutrition deficiency reduced by over half (from 7 to 3 diagnoses), whereas infectious disease diagnoses increased from 7 to 8. The short timeframe between measures relative to the chronicity of the disease conditions identified explains this unremarkable change in health status.

As with the Wicking I participant group, the physical health profile of Wicking II participants was representative, if not slightly worse, than that measured in another study of the prevalence of health issues in a population of older people experiencing homeless in Melbourne (Table 13). 156

Table 13 Physical health problems of an older Melbourne homelessness population excluding substance abuse disorders (based on respondents' reports)<sup>156</sup>

Physical health problems	Men (%)	Women (%)	То	tal
			Number	%
Musculoskeletal problems	47.3	53.1	61	48.8
Cardiovascular problems	43.0	40.6	53	42.4
Neurological disorders	20.4	15.6	24	19.2
Endocrine disorders	11.8	21.9	18	14.4
Digestive system problems	12.9	9.4	15	12.0
Respiratory problems	9.7	12.5	13	10.4
Tumour	3.2	18.8	9	7.2

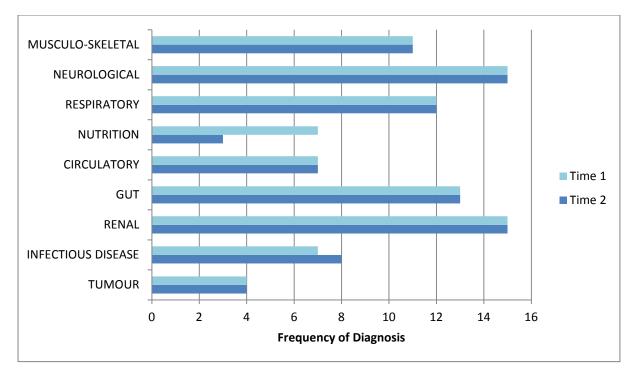


Figure 32 Changes in general health for Wicking II participants (Time 1- Outset, Time 2 - Completion)

### 4.7.3.2 Subjective wellbeing

Based on these measures reported above, participants' state of wellbeing was seen to improve over the project period. These findings were also reflected in another novel self-rated qualitative measure used in this study. Participants were asked to respond to the question, 'What word would best describe your life at the moment?' This question was asked of all participants at the commencement and again on the completion of their participation. A graded representation of the responses is shown in Figure 33. A small panel of staff, blind to the identity of the participant, were asked to provide subjective ratings for the words (between 0 to 10, with zero representing the lowest negative rating and 10 representing the highest positive rating). The outcomes of these ratings are indicated by blue columns in Figure 33. This shows that participants subjectively rated their life/wellbeing as having improved by almost 50% over the duration of their participation.

Although showing less negative responses over time compared with a control group, the overall rating of words chosen by participants of the Wicking I project at Time 2 indicated very little change. Generally, at Time 2, participant responses reflected very little of the positivity and hope expressed by Wicking II participants. It is difficult to draw inferences from these findings; however, exit planning for Wicking II participants was more structured, with participants being more involved in the decision making process.

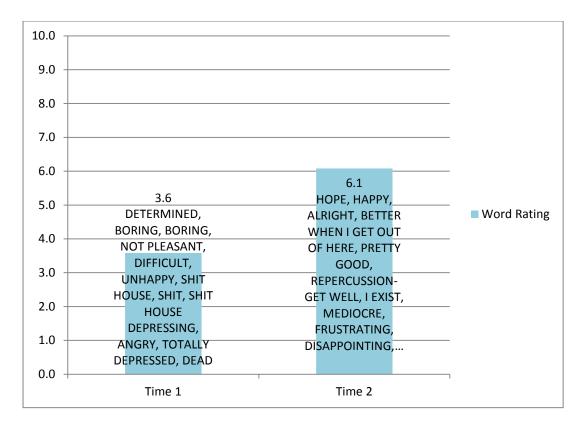


Figure 33 Graded subjective descriptors of life quality for Wicking II participants

### 4.7.3.3 Contact with Emergency Services

Figure 34 shows emergency services data that were collected for participants across two periods. Time 1 represents the six months preceding participants' involvement in the project and Time 2 represents the final six months of their involvement.

The average number of nights spent in hospital fell from 14.1 to 3.3 from pre-project to the end of the project (t(14) = 2.714, p = .017, d = 0.87). The average number of contacts with ambulances fell from 9 to 3.7 (t(14) = 1.509, p = .154, d = 0.48). The average number of emergency department presentations dropped from 6.3 to 2.1 (t(14) = 3.466, p = .004, d = 1.13). The average number of contacts with police decreased from 3.9 to 0.8 (t(14) = 2.421, p = .030, d = 0.73).

Although the reductions did not reach statistical significance at the study's conservative alpha level, number of nights spent in hospital, number of emergency department presentations, and contacts with police showed a trend toward significance, and all were associated with moderate to large effect sizes. The average number of contacts with ambulances was associated with a small to moderate effect size. The magnitude of these effect sizes and trends towards significance suggest the real clinical importance of the reductions in emergency service contacts for the participants.

Another implication of this reduction in emergency service contact, beyond its impact on participant wellbeing, is the economic impact of the reduction in costs incurred by government agencies such as health and justice services. These costs will be further analysed and discussed later in this report (Chapter 4.9.1 Wicking II project economic evaluation).

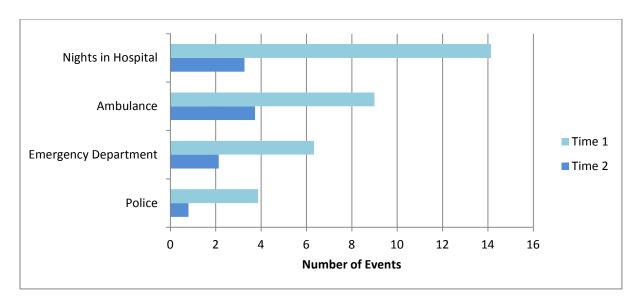


Figure 34 Contact with emergency services pre-project to end of the Wicking II project

## 4.7.3.4 One size does not fit all

There was one participant in particular in the Wicking II project who did not adjust well to the program. In the absence of alcohol, this gentleman demonstrated the skills to live independently but there were rarely times when alcohol was not present. Despite the intensity of the psychosocial support that he received, he continued to engage in frequent episodes of absconding, excessive drinking and hospitalisation, and there was very little change in the frequency or severity of the challenging behaviour that he exhibited.

During his nine months of participation in the program (between periods of binge drinking), he was capable of managing his own activities of daily living, frequently cooked independently for himself and others and kept his room in a tidy and clean state. His support requirements were not focussed on activities of daily living or physical needs but, rather, to assist him with social support and to manage behavioural concerns associated with his alcohol abuse and brain injury. His planning, organising, problem solving and reasoning skills were all reduced as a result of his brain injury. Therefore, his decisions or requests were often not well thought out and lacked understanding of the potential consequences of his decision. As a result, his finances were managed by a state-appointed administrator and decision making around his lifestyle and accommodation needs had, for several years, been managed by a state-appointed advocate guardian.

Generally, this gentleman was jovial, congenial, social and conversive, even while he was moderately intoxicated. Only occasionally would he exhibit aggressive behaviour, generally following many days of prolonged and excessive drinking. When intoxicated, he would present a significant risk to himself in the community, having been assaulted on several occasions and found unconscious by police and ambulance officers on numerous occasions. On many occasions, he would be very outspoken about the perceived injustices that he had faced throughout his life, which he rarely attributed to consequences of his own actions.

Understandably, independence and choice and control were paramount to him. Therefore, being advised against any decisions that he made or having a request denied would result in him becoming very upset, which often led to extended binge-drinking episodes, verbal aggression or him leaving the facility for extended periods. Commonly, during these times. he would be extremely

sensitive to attempts by others to manage his behaviour, which he would perceive as 'others' trying to control him or deprive him of his liberties and independence. For example, he would often claim that he had been deprived of his rights and was being 'treated like an animal'. At times he could become obsessively focussed on his financial status and suspicious that others (including the facility) were cheating him of his money. These responses would most frequently occur when he was highly intoxicated.

During his participation in the Wicking program, this gentleman demonstrated a range of challenging behaviours, including:

- being in an agitated state where his mood was hostile and defensive
- leaving the premises for extended periods (up to two days), without notifying staff
- verbal aggression or threats (e.g. yelling, 'Give me alcohol or I'll leave')
- physical aggression towards people by standing too close or 'over' others in a threatening manner or lunging, pushing, grabbing or spitting on people
- physical aggression towards objects such as kicking the office door or window
- requesting/taking alcohol from others
- compromising his safety by going to the community when heavily intoxicated.

Eventually this gentleman chose to withdraw his participation from the Wicking II project and leave the facility in order to pursue an opportunity to enrol in an extended 16-week alcohol rehabilitation program. Unfortunately, after 14 weeks of successful participation, he left the program and its accommodation without notice, avoiding any attempts to establish contact with him for more than three months. Reoccurring hospital emergency department presentations saw his health in a state of rapid decline due to self-neglect and alcohol toxicity. He died five months later from the resulting gastrointestinal complications.

A review of this gentleman's experience in the Wicking II project reveals significant features of his persona that contributed toward an unsuccessful outcome. This included his strong desire to attain freedom, independence and control over his life, which when achieved rapidly led to a spiralling decline in his health and wellbeing. This combined with traits of a vehement dislike of rules and restrictions and suspicion and paranoia about the intensions and motives of support staff were significant barriers to the establishment of rapport and productive engagement. Similarly, another participant in the Wicking I project displayed a similar profile to this gentleman and the outcome of his participation was also unsuccessful.

## Cycle stopped

Engaging, cheeky, affable gentleman. Whirlwind, constant intoxication and falls. Sounds of skull connecting with asphalt, sickening sound. Addiction funded by well-intended generous strangers, begging was source of income, a means to intoxication and escape.

Previous SRS and crisis accommodation, scary places he recalled. Stand-over men, taking his money and cigarettes. No privacy. No safety. Eventual eviction from yet another SRS marked a return to the cycle of homelessness.

Eight Emergency presentations to the one hospital within a month led to a dedicated hospital social worker to step beyond her mandated episodes of engagement to advocate strongly. 'He will be dead soon', she said, 'if nothing is done'. Most work occurred when T was in the waiting room or not even in the hospital. A chance encounter with a colleague who knew of the Wicking II project led to a referral.

Took some time to accept support. Understandably, after at least six years of not having security of tenure, own room, privacy, dignity. First months, regularly accessed alcohol with money gained from begging. High frequency intoxications often resulted in serious injuries – mainly to his head due to falls. These incidents occurred several times per week and sometimes several per day.

Determined staff would seek T out in the community when he missed a scheduled meeting, meal or outing. Usually he was found at the local shops. Staff persisted in encouraging his return to a safe environment. 'Why?' he would ask. Staff responded 'Because we care.' Tears were frequent in response to this statement. He hadn't felt cared for in a very long time.

Banned from the local bottle shop. With access denied along with consistent encouragement and care from staff, T dramatically reduced the episodes of intoxication and resulting injuries. Instead of begging, he now chose to purchase snacks and hire videos with staff assistance. These were taken home and consumed in the warmth and safety of his room. He loves watching his movies and the footy (his beloved Collingwood). His room is strewn with Collingwood paraphernalia and a large semi-nude print that called to him from hard rubbish.

Although proud of his achievements, he is unable to sustain his improvements for long periods with some setbacks interspersed with periods of 'safe' consumption.

Binges now occur approximately fortnightly as opposed to almost daily. He strongly identifies with the community to which he now belongs – the friendships, the camaraderie and the continued amazement that people still care even after he 'stuffs up'.

# 4.8 Behaviour frequency observations

## 4.8.1.1 Behavioural changes over time

Behaviour frequency data were collected for all participants. The average length of time spent in the project was 11.2 months (*SD*=5.2 months). As such, data for three consecutive (quarterly – three-month) periods were available for most of the sample (10 participants). These three periods were included in analyses to best represent behavioural change over time while minimising loss of statistical power. 'Aggressive behaviour' includes incidents of verbal aggression and physical aggression. 'Observed intoxication' includes incidents where participants were observed by staff to have been intoxicated on alcohol and/or drugs. 'Emergency services' includes hospital admissions, emergency department presentations and police incidents. 'Overall' includes the aforementioned incidents, as well as the submission of incident reports with cross checking to ensure that there was no duplication of reported incidents.

Variables were assessed statistically and visually and determined to be normally distributed. Repeated measures analysis of variance (ANOVA) following a general linear design was then used for analyses. Greenhouse-Geisser corrections were used where sphericity was violated. 157,158

A repeated measures ANOVA with a Greenhouse-Geisser correction determined that there was no statistically significant difference between overall mean frequencies of behaviours between the three time points (Figure 35–Figure 38). However, average behaviour frequencies measured in all four categories were lower toward the end of participants' participation than they were at the beginning. One explanation for the small amount of measurable change in behaviour could lie in the relatively short timeframe (nine months) relative to the chronicity of the behaviour exhibited.

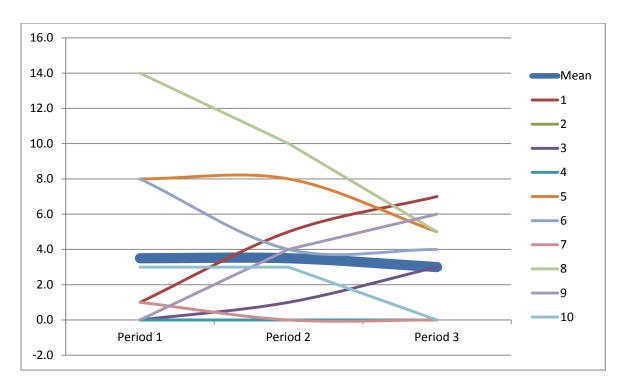


Figure 35 Frequency of aggressive behaviour among Wicking II participants (F(1.141, 10.271) = .144, p = .745)

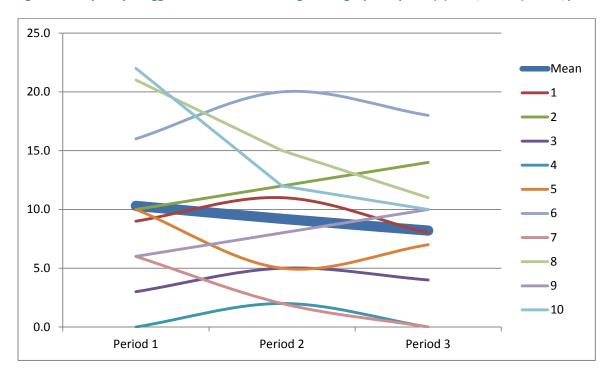


Figure 36 Frequency of incidents of intoxication among Wicking II participants (F(1.223, 11.011) = 1.129, p = .326)

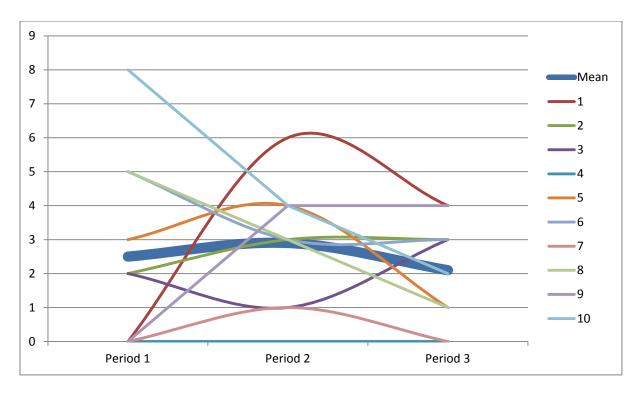


Figure 37 Frequency of engagement with emergency services among Wicking II participants (F(1.339,12.046) = .454, p = .569)

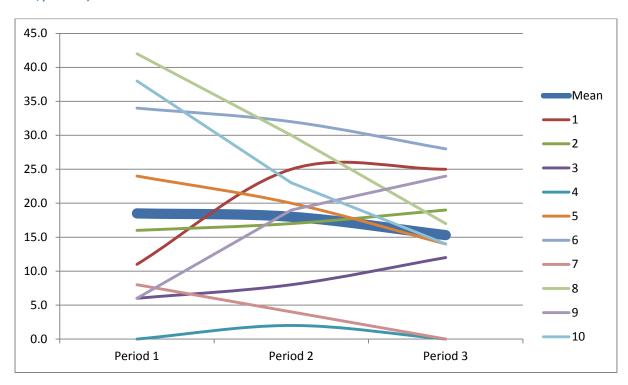


Figure 38 Frequency of the overall number of behaviours of concern for Wicking II participants (F(1.052, 9.47) = .545, p = .487)

In the Wicking I project, comparisons of behaviour frequencies over time demonstrated that participant behaviour was characterised by a 'hill-shaped curve', with the frequency of challenging behaviours exhibited by participants increasing to a peak after approximately there months, then reducing again over the following two months (Figure 9). This trend was not as apparent in the

Wicking II behaviour frequency data. Differences in these findings may be due to differences in program models (i.e. stand-alone versus facility integration), population demographics or methodological differences in data collection protocols (e.g. quarterly measures in this study compared to monthly measures in the Wicking I study).

## 4.8.1.2 Behaviour frequency exploratory analyses

Further exploratory analyses were conducted for those participants who remained in the study for four periods (n=7). Figure 39 to Figure 42 display the frequency of aggressive behaviour, observed intoxication, emergency service engagement and overall behaviours. For these exploratory analyses, statistical significance was set at p < .05.

A repeated measures ANOVA determined that mean frequency of only observed intoxications differed statistically significantly across all time points (F(3, 18) = 3.506, p = .037). Post hoc tests using the Bonferroni correction did not reveal any statistically significant differences between any specific time points. More notable decreases in the frequency of measured behaviours were also observed, although not to a level of statistical significance. A similar pattern of increased or persisting levels of behaviour frequency over the initial periods of participation, as noted in the Wicking I project, also began to appear.

These exploratory analyses suggest that continued involvement in the study might be associated with reduced frequency of challenging behaviour (in particular, observed intoxication).

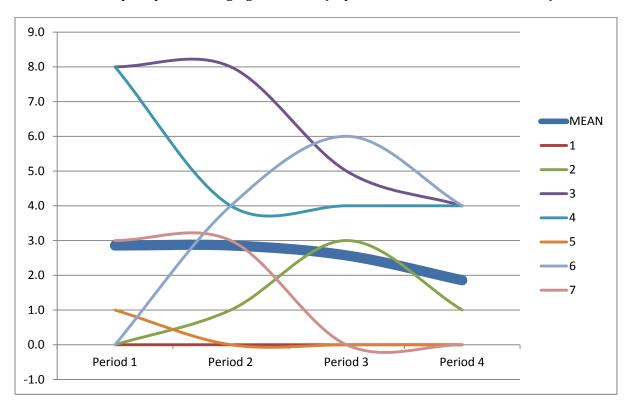


Figure 39 Frequency of aggressive behaviour among Wicking II participants (F(1.398, 8.389) = .524, p = .548)

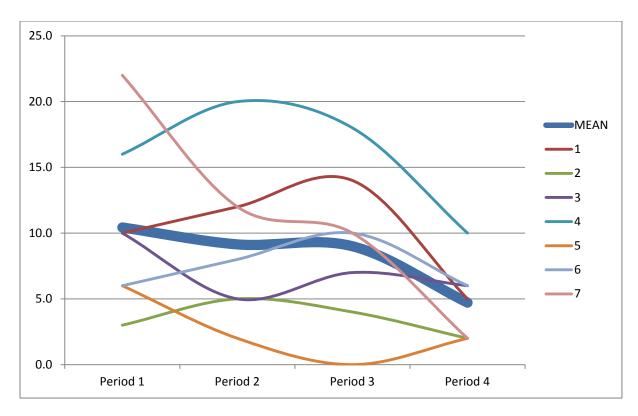


Figure 40 Frequency of incidents of intoxication among Wicking II participants occurring (F(3, 18) = 3.506, p = .037)

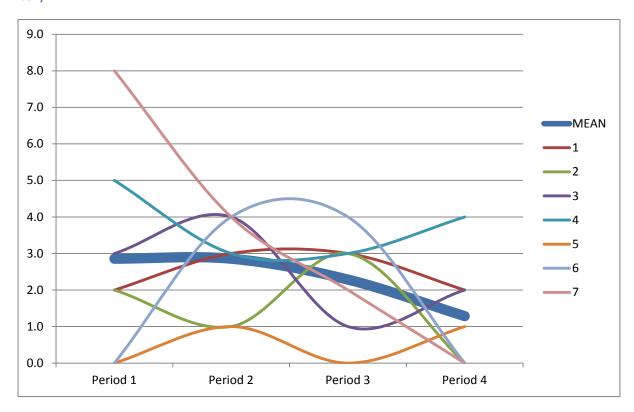


Figure 41 Frequency of engagement with emergency services among Wicking II participants (F(3, 18) = 1.277, p = .312).

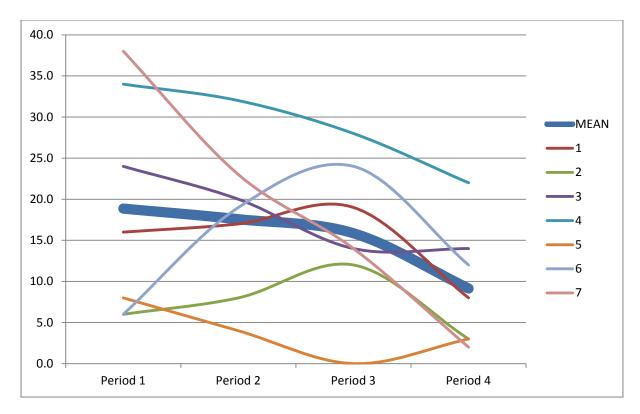


Figure 42 Frequency of the overall number of behaviours of concern of Wicking II participants (F(1.366, 8.194) = 2.99, p = .116)

## 4.8.1.3 Relationships between variables

Pearson's correlations were used to investigate relationships between changes in clinically validated measures and subject demographic data. Correlations that were significant at the 0.05 level (2-tailed) are:

- older age of when participant drinking commenced was significantly associated with older age of participant at the start of the Wicking II project (r = .646, p = .009)
- older age of when participant drinking commenced was significantly associated with a decrease in reported depressive symptoms as measured by the Hospital Anxiety and Depression Scale (HADS) (r = -.662, p = .019)
- decreases in the level of problem drinking as measured by the Alcohol Use Disorders Identification Test (AUDIT) Total Score was significantly associated with increases in satisfaction with life as measured by the Satisfaction with Life Scale (SWLS) Total Score (r = -0.684, p = .014) (note: one outlier case might be causing the significant finding)
- decreases in the level of problem drinking as measured by the Alcohol Use Disorders Identification Test (AUDIT) Total Score was significantly associated with increases in community integration as measured by the Community Integration Questionnaire (CIQ) Overall Score (r = -.699, p = .011)
- decreases in psychosocial dysfunction as measured by the Health of the Nation Outcome Scales (HoNOS) Total Score was significantly associated with increases in community integration as measured by the Community Integration Questionnaire (CIQ) Overall Score (r = -.790, p = .002)
- decreases in neuropsychiatric symptomatology severity as measured by the Neuropsychiatric Inventory (NPI) Severity Score was significantly associated with decreases in challenging behaviour as measured by The Overt Behaviour Scale (OBS) Total Score (r = .628, p = .022).

# 4.9 Frequency data for economic modelling

### 4.9.1 Wicking II project economic evaluation

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(Centre for Health Policy, School of Population and Global Health, University of Melbourne)

The cost of homelessness encompasses direct costs, including shelters and services, as well as indirect costs (which economists refer to as externalities), such as increased use of health services, policing and the criminal justice system. In a study of 2578 homeless and marginally housed persons, factors associated with different patterns of emergency department use were assessed. Findings showed that 40.4% of respondents had one or more emergency department encounters in the previous year, of which almost 8% exhibited high rates of use (more than three visits). Factors associated with high use rates included unstable housing, victimisation, arrests, physical and mental illness, and substance abuse. An evaluation was conducted on the economic impact of decreased emergency service usage resulting from participation in the Wicking II project.

### 4.9.1.1 Methods

The purpose of this evaluation was to estimate economic costs incurred by both health and justice departments by participants of the Wicking II project six months before and after enrolment, in order to estimate the potential benefits in terms of reduced costs for government. The four main recorded services used were the number of police contacts, ambulance pick-ups, emergency presentations and hospital nights' stay.

Unit costs for each of these services were not easy to value, as the engagements by the study participants with the justice or health departments were wide ranging. For example, police engagements could involve arrests or the issuing of fines and welfare checks, and hospital admissions could be a night's stay in standard medical wards or in intensive care units – the details of each participant's encounters or resource use were not available. As such, for police contact, a general estimate that would encompass all police encounters (average cost per criminal incident) was used. For health-related services, costs that most closely match the potential service used were applied and conservative estimates were used when there were big cost differences depending on the type of service use. All unit costs were obtained from literature searches and from reports of relevant agencies. All costs were inflated with the appropriate consumer price index<sup>160</sup> to reflect 2015 Australian dollars. Victoria-specific costs were used where available. Table 14 shows the unit costs of the four main services used and their sources.

Table 14 Unit cost for each emergency service resource used in the Wicking II project

Resource Average unit cost in 2015 Australian dollars		Source	
Police	\$1694	per criminal incident	FaHCSIA 2012 report <sup>161</sup>
Emergency	6402	nor non admitted presentation	NHCDC Australian Public Hospitals Cost
presentation \$403		per non-admitted presentation	Report 2012-2013 <sup>162</sup>
Ambulance use	\$1146	per emergency transport fee	Ambulance Victoria fee schedule 2015-
Ambulance use	\$1146	(metropolitan area)	16 <sup>163</sup>
Hannital minht	¢840	per inpatient bed day for mental health	NSW Health Costs of Care Standard 2009-
Hospital night	\$849	treatment	2010 <sup>164</sup>

The total cost of resource use by each participant was obtained by multiplying the number of resource use by its respective unit cost. From this, the average total cost and differences in cost incurred by all participants six months before and after enrolment could be determined, with the difference providing an estimate of the likely cost savings to government of the program in terms of reduced service use.

#### 4.9.1.2 Results

The total number of participants enrolled in the Wicking Project for whom data were available was 15. Table 15 shows the resources used and the total costs incurred six months before and after enrolment into the program.

Table 15 Emergency service resource use and cost pre- and post-enrolment and changes in costs over time

	P	Pre-enrolment		st-enrolment	Cost savings per person
Resource (6-monthly)	Numbers per person (95% CI)	Cost per person, \$ (95% CI)	Numbers per person (95% CI)	Cost per person, \$ (95% CI)	\$ (95% CI)
Police	3.1	5,307	0.8	1,355	3,952
encounters	(1.1: 5.2)	(1,872: 8,742)	(0.1: 1.5)	(169:2,542)	(1,454:6,451)
Emergency	6.3	2,550	2.1	859	1,691
presentations	(3.5:9.1)	(1,417:3,682)	(1.4:2.9)	(557:1,161)	(644:2,737)
Ambulance	9.0	10,314	3.7	4,278	6,036
use	(0.6:17.4)	(692:19,935)	(2.1:5.3)	(2,429:6,128)	(2,544:14,615)
Hospital night stays	14.1 (4.9:23.4)	12,003 (4,166:19,841)	3.3 (0.2:6.3)	2,774 (171:5,378)	9,229 (1,937:16,521)
Total cost of government services	-	30,174 (14,017 - 46,332)	-	9,267 (5,055 - 13,478)	20,907 (7,384 - 34,432)

<sup>\*</sup>Total costs may not tally due to rounding, 95% CI are approximations basically on normality assumption and cost are in 2015 Australian dollars

The total numbers of resource use across all services were reduced post-enrolment. Police encounters dropped from 3.1 pre-enrolment to 0.8 post-enrolment per person – a 74% reduction. For health service use, the number of emergency presentations per person dropped from 6.3 to 2.1 (66% reduction), ambulance use went from 9.0 to 3.7 (down by 59%) and the greatest decrease (77%) was observed for total number of hospital nights, from 14.1 to 3.3.

The cost of government services incurred by the 15 participants six months before enrolling in the project totalled \$452,617; this value dropped to \$139,001 due to the overall reduction in services used six months after enrolment (Table 2). Therefore, the difference in cost pre- and post-enrolment was \$313,617, which equates to a cost saving to the government of \$20,908 per participant (95%CI \$7,384–\$34,432), with the largest savings for hospital stays and ambulance use.

### 4.9.1.3 Economic evaluation conclusions

Overall, participants enrolled in the Wicking program were observed to have fewer police encounters, fewer emergency presentations, less ambulance use and fewer days of hospital stay six months after enrolment compared to the six months before, all of which contributes to a decrease in resource use. Our calculations show that a potential cost saving of up to \$20,000 per participant to the health and justice departments is feasible from the program. Costs were rough estimated for each service used and were not specific to the actual services used; therefore, this could have under- or over-estimated the actual costs involved. In addition, data on service use pre-enrolment was used to estimate the likely service use had the participants not been enrolled in the program.

Again this may have produced an under- or over-estimate of the likely cost savings if a particular acute phase for the participants had subsided on enrolment. Also, these costs estimates are based on only a small sample of clients; therefore, there is still a considerable amount of uncertainty around the true cost savings as demonstrated by the large confidence intervals.

### 4.9.2 Project service delivery cost comparison between Wicking I and Wicking II models

The purpose of this investigation was to compare the running costs between the Wicking I project's 'stand-alone' care model within a dedicated four-bedroom home and the Wicking II's 'communal living' model within a sixty-bed residential aged care facility. Based on operational budgets, service costs were identified and measured in order to determine which care model was more cost-effective. The average funding shortfall per client (cost associated with delivering the specialised Wicking support program over and above the government-funded cost of residential aged care) was calculated for both projects.

Table 16 shows the average daily costs and subsidy income for each the two Wicking programs. To give an accurate comparison. the expenses for the Wicking I project have been grossed up at the same rate as the increase to the Aged Pension over the period between the two projects. Both scenarios show the same daily income as calculated for the Wicking II project so that the 'shortfall' can be compared on a 'like-for-like' basis.

To calculate these numbers, the total expenses and total government funding were divided by the number of clients and total number of care days delivered to create an 'average daily rate per client'. To make these averages a true representation of the study group, one participant who recorded a second short stay during the Wicking I project following hospitalisation and one participant's short-term palliative stay during the Wicking II project were discounted from the calculations, as these stays did not conform to the programs' purposes.

Table 16 Participant support cost for the Wicking I and Wicking II projects

	Wicking I project 2009 (grossed up for pension at 2015)	Wicking II project 2015
Total support cost		_
Per client per day	\$264	\$287
Average days of care	203	287
Total cost per client	\$53,516	\$82,370
Income from government		
Average per client per day	\$165	\$165
Shortfall per client per day	\$98	\$122
Total shortfall for an average client over their average length of stay	\$19,953	\$34,919
Total shortfall for an average client over a standardised 6 months	\$17,885	\$22,265

For most clients, the program of the Wicking I project was more cost effective than the Wicking II project. The 'days of care' shows a faster improvement for clients within this model, while the 'per client per day' cost shows that Wicking I project was also more cost effective.

## A long journey to happiness

Serious risk. Life on the edge. Safety compromised frequently. Found incoherent in parklands, local rooming houses, disreputable places, laying barely conscious on the street. Assaulted, robbed, abused.

Always a strong desire to change her life. Insight lost into the impact and destruction that addiction has had in her life, yet a strong sense of guilt remained.

After a long journey. At time of writing J had abstained from alcohol for over two years. She was living independently, volunteering, engaging in her community and enjoying life.

Reuniting with her family. Happy in thought of her future life ahead.

# 5 Discussion – Wicking I and Wicking II key project learning themes

In the field of research into the delivery of aged care to a population of people experiencing brain injury, in particular alcohol addiction, the gold standard of research design, the randomised controlled trial, can be extremely difficult, or impossible, to achieve. This is due to the high prevalence of varied and multiple pathologies, both physical and psychological, among members of this group; their frequently chaotic and disenfranchised lifestyles, including homelessness; and the high attrition rates, small sample sizes and limited survival times. Furthermore, a number of important issues need to be considered including disparities in access to and length of engagement within social welfare and health care services, frequent stigmatisation of individuals, their behaviour or lifestyles, and the presence of significant barriers to establishing rapport and trusting relationships.

The Wicking projects were therefore evaluated using action research methodologies, which were exploratory in nature with a mixed methods design incorporating both qualitative and quantitative data. The outcomes have elicited essential components of a care model designed to provide aged care to people living with an ARBI. These include the delivery of a harm-minimisation program involving controlled drinking and smoking programs for those who were actively drinking or smoking; centring the individual in the delivery of a psychosocial model of care; working together with neuropsychologists in the application of behaviour management strategies based on functional behaviour assessments and the development of behaviour support plans; developing and delivering individualised structured activity programs; and delivering care in a purpose-built environment by a team of highly trained and skilled personnel.

Essentially the successful outcomes achieved for the participants in the Wicking projects have led to a greater understanding of what is achievable through a highly supportive model of residential care. It has also led to a shift in emphasis and direction from traditional models of residential care, where residents are expected to adapt and assimilate to the aged care environment, to a more specialised model that truly focuses on individualised care.

With a high percentage of people presenting with long and established histories of drinking, smoking, gambling, crime and acquired brain injuries, not many aged care services are willing, or have sufficient expertise, to allow clients their preferred lifestyle choice. Often service providers are challenged to support the diversity of need exhibited within a single service setting because of the scarcity of trained staff and available resources. Consequently, for support services to deliver appropriate and effective care, staff must possess knowledge of the underlying, and often multifactorial, causes of the behaviour, and they must also be skilled in delivering effective responses, taking into consideration the limited cognitive capacity of the individuals concerned.

# **5.1** Structured activity/recreation program

In Wicking I, a structured activity program was delivered by one recreation officer working with four clients for two days a week, essentially providing each participant an average of four hours of dedicated recreational support each week. As the program progressed, it became apparent that participants were bored on the days when the program was not running, which is characteristic of people with an ARBI. Participants experienced great difficulty motivating themselves to engage in positive pursuits or pastimes and usually required significant support and prompting, especially when the participant was new to the program. Inevitably, the participant would fall back on a long-

established habit of alleviating boredom by drinking alcohol. To minimise this scenario, the structured activity program of the Wicking II program was delivered by attendant carers providing 25 hours of one-on-one individualised structured activity support each week. At the start of the program, this level of support was effective and appropriate. Most participants stepped down the level of support they required, concluding the program with approximately 8 hours of structured activity support each week.

# 5.2 Alcohol and cigarette program

The alcohol and cigarette program remained relatively unchanged between the Wicking I and Wicking II Projects, as this program had been trialled and developed over 25 years of delivering Wintringham residential aged care. However, participants in Wicking II adhered to their program a little more successfully, as they appeared to be encouraged by other residents who adhered to their programs. Another influencing factor was that Wicking II participants were frequently accompanied by carers while in the community, who discouraged the purchase of additional alcohol through gentle persuasion, encouragement and diversion.

# 5.3 Stand-alone versus communal living

Some discussion is warranted in contrasting the Wicking I Project's 'stand-alone' care model within a dedicated four-bedroom home and the Wicking II's 'communal living' model within a sixty-bed residential aged care facility. The Wicking II Advisory Committee believed that an 'integrated Wicking I model' would demonstrate cost savings relative to the Wicking II model (addressed in Economic Outcomes) and that there would also other psychosocial benefits:

- There would be less conflict between participants of the Wicking II projects as there would be greater dilution of conflicting behaviour between Wicking II participants as they intermingled with other non-Wicking residents.
- The experience of delivering intensive support programs to people living with complex behaviour support needs would enhance opportunities for the training of behaviour management strategies to all staff, thus having a positive impact on behaviour management across the entire residential site.
- Synergistic benefits between Wicking II and non-Wicking staff workloads could flow on to benefit Wicking II participants and non-Wicking residents ('I will help you now, assuming you will help me later').

The Wintringham Eunice Seddon Facility was selected as the site for the Wicking II program because it was only two years old and had a new intake of staff and residents. It was expected that locating the project at this relatively new facility would have a positive impact on supporting Wicking and non-Wicking staff with behaviour management, which would ultimately have a positive impact on the care of all residents on the site.

There were several key points of learning when comparing the two models of living environments:

Both had elements of competition/conflict/rivalry between residents. The Wicking II model
elicited slightly more episodes of physical aggression due to having an additional 55 nonWicking co-residents on site who were not receiving the program. This fostered negative
attributions by non-Wicking co-residents to program participants, such as resentment, fear,
distrust, and seen as being rewarded for negative behaviour.

- Both the Wicking I and the Wicking II models were unsuccessful in discouraging the establishment of an informal 'drinking culture' among participants; however, the drinking culture expressed itself differently in the two models. It was more common for Wicking II participants residing within a larger facility to collude with non-Wicking residents who were also drinkers. This had the positive effect of increasing the number and range of relationships shared by participants, but also lead to broader, negative attributions directed toward the collective group of alcohol consumers within the facility by co-residents and a number of staff. A generalisation emerged in which all residents who drank alcohol excessively within the facility were associated with the Wicking II program. Indeed, during this period, many alcohol-related incidents that did not involve a Wicking II participant were negatively associated with the project. For Wicking I participants, the informal drinking culture resulted in 'room parties' in which all four residents pooled their resources and consumed large quantities of alcohol together.
- Both the Wicking I and the Wicking II projects experienced issues of conflict between staff members. For the Wicking I project, this was principally driven by perceptions of non-compliance or non-adherence with service delivery/program guidelines, particularly in behaviour management (i.e. breaking the 'rules' of routine and consistency).
- Staff conflict in the Wicking II project was principally driven by perceptions of unequal
  workloads. Non-Wicking staff would witness Wicking II staff sitting and chatting with Wicking
  II participants while they (non-Wicking staff) were busy attending to other resident's needs
  (attending to personal care and activities of daily living). This was interpreted as there being
  disproportionate workloads between staff, which led to resentment, complaints and mistrust
  among staff members.
- Some participants assimilated more readily to the intimacy of the smaller Wicking I
  environment while others assimilated better to the larger, more communal Wicking II
  environment. It is believed that this ultimately related to differences in personality types: those
  exhibiting more introverted characteristics appeared more comfortable in the more intimate
  setting (Wicking I) and those with a more social, extroverted personality traits appeared more
  comfortable in the Wicking II environment.
- The co-location of the Wicking II project within a large facility made behaviour training opportunities more readily available to all staff (Wicking and non-Wicking) and senior management. The Care Staff Survey reported herein indicated that this had an overall positive impact on staff confidence when supporting residents living with complex behaviours. Reportedly, an overall positive impact was observed on the delivery of effective behaviour management planning across the whole site, which has endured post Wicking II project.
- When a participant had 'completed' their participation in the Wicking I project, they were offered transition of residency into other Wintringham facilities, which in turn allowed for a smooth transition for the next Wicking I participant to casually enter the Wicking I household when they were ready.
  - The transitioning of participants into and out of the large residential aged care facility of the Wicking II project proved considerably more challenging. A larger than expected disruptive impact was identified for the Eunice Seddon Site and its flow-on effects on Wicking and non-Wicking residents. Several factors were seen to disrupt the smooth transition of participants:
    - The transition process for Wicking II participants was not clear, particularly for identifying and communicating when a Wicking II participant had completed their program and what the next housing option was to be for this participant.

- Some Wicking II participants expressed a clear desire to remain in residence at the
  Eunice Seddon Home; however, while remaining at the site following their
  participation, these same residents were still being viewed as Wicking II participants.
  This lead to confusion as to the allocation of staffing resources, particularly when there
  was a relapse in behaviour.
- Some Wicking II participants expressed a clear desire to live independently, but lacked the necessary functional or cognitive skills to arrange their own housing and support, so transition was delayed while support for the desired move was arranged.

In effect, the same flexibility that allowed for an individually tailored pace of admission for Wicking II participants also led to delays during which time non-Wicking residents were admitted into the next vacant bed available. A key performance indicator in any aged care facility is optimal bed occupancy levels – an empty bed does not receive funding. It is therefore understandable that the need for a bed to be filled could compromise the admission of a Wicking II participant who may not necessarily be 100% ready to enter the program. Ultimately, this interfered with the admission process for Wicking II participants, who by virtue of their often pre-participatory chaotic state needed a room when they were ready, not when the residential care bed was ready. This single factor adversely affected participant numbers in the Wicking II project. The same issues did not occur in the Wicking I project, as it was a stand-alone facility with its beds dedicated solely for the use of Wicking project participants.

# 5.4 Change associated with the introduction of a new program

The Wicking II program was implemented into the Eunice Seddon Home with the intention of providing extra expertise and support to the site, founded on a well-versed change management strategy. <sup>166</sup> There was a pressing need to support a cohort of 'Wicking suitable' clients and to provide extra training for staff and support for the residents in the relatively new care facility. In effect, introducing the program to meet the needs of an assessed urgency adversely impacted the partnership between the residential care facility and the Wicking program. While the intention was honourable, the rapid introduction of the program caused a level of suspicion and concern among some staff and, ultimately, some resistance to the program initially.

To facilitate the more intensive, structured activity program that the Wicking II project offered prospective participants, care staff were employed specifically and trained to facilitate the unique program. It quickly became apparent that non-Wicking II staff developed a negative attitude toward some of the newly trained Wicking II staff. They were perceived as 'extra staff' but not additional 'hands-on' staff that could help with the day-to-day direct care of non-Wicking II residents. Many Wicking staff reported they felt the need to justify their roles to non-Wicking II staff. The ideal scenario of an evolving synergy between Wicking II and non-Wicking II staff did not occur initially.

During the early stages of the Wicking II program, many facility staff reported a sense of a chaos that the introduction of Wicking II participants had bought to the site. There were comments like, "There are so many more incidents now (since the Wicking II program commenced)', 'A greater workload has resulted from the need to support this erratic client group' and 'The program affects the overall homeliness of the facility for other residents and staff'.

An early internal review of Wicking II staffing integration into the Eunice Seddon Home and cohesion with Eunice Seddon Management provided the following rationales for the slow integration and acceptance of the Wicking II program:

- While information was available before the Wicking program began, the pragmatic bringing forward of the program resulted in a shorter lead-up time to establish effective communication strategies.
- More education was needed that specifically outlined the roles of Wicking II staff and how they would work together with non-Wicking II staff, to decrease confusion among all staff.
- There was limited understanding of the aims of the Wicking II program, its skill base and its expertise, which led to the development of an 'us and them' mentality among staff.
- Wicking II staff employed to support participants in structured activity programs were viewed by a small number of non-Wicking staff as 'bludgers' (or shirking work responsibilities) because a large component of the Wicking II staff's role involved socialisation with participants rather than delivering direct personal care.
- As the Eunice Seddon site was still relatively new, a 'esprit de corp' was yet to form and there was an overall general resistance to the process of change.
- In the time leading up to the program, there was a change of facility manager at the project site that, in the short term, further contributed to the site's vulnerability.
- Having undergone a change in management, some site staff reported a perceived lack of unified leadership among supervisory staff, which perpetuated rumours and suspicion.
- This same suspicion among staff influenced negative perceptions as to the intention of 'research' at the site and that its involvement would place undue scrutiny and judgment on the practices of all staff.

Following some intense support and supervision from senior management, a range of actions were put in place to overcome these initial difficulties. The new vision included:

- empowering the site/facility manager to oversee and provide administrative support and supervision of all staff across all aspects of the project
- empowering the site/facility manager to have overarching control and responsibility for all aspects of residential care for all residents (including Wicking II project participants)
- some changes in staffing
- clarifying the roles of all Wicking II staff, including the research manager and case manager, so that all parties better understood these roles
- having formal meetings between the Wicking II research manager and the site/facility
  manager, to exchange ideas and concerns about how the Wicking II program was working at
  the site and to further develop these relationships which Kotter (2012) expresses as a strategy
  to develop a 'powerful coalition' 1666
- encouraging regular formal and informal communication interchanges between all Wicking II and non-Wicking facility staff
- encouraging Wicking II and non-Wicking staff to promptly raise concerns and formally discuss issues or problems with each other or with their immediate supervisors
- inviting and actively supporting Wicking II staff to participate in staff meetings, training and social functions in which non-Wicking staff were involved.

Emphasis was placed on the importance of the project's interventions to participant outcomes and the need for all staff to work together in the best interests of the participants and other residents. It was important to put the participant at the centre of all work being undertaken by the team, in order to meet the participant's needs and compliance measures imposed within the research methodology – 'A clear vision helped everyone understand. (Kotter 2012). Acceptance and ownership of the program was fostered over time by allowing all staff to have input into the evolution of the program and to reflect on the needs of all staff and all residents at the site, irrespective of which program they belonged to.

This approach was consistent with the quality improvement process in which each staff member had a responsibility, according to their job description, to actively assist the practice of quality management and to work together as a cohesive team to achieve continuous improvement and accreditation. Over time, a greater understanding developed around each person's role, and good supportive working relationships were established between Wicking II and non-Wicking staff.

The number of incidents, feedback and complaint forms before, during and after Wicking II did not show a remarkable variance during the life of the project (Figure 43). This 'helicopter view of incidents' did not in any way analyse the severity of incidents. Further analyses highlighted an increase in the number of episodes of physical aggression toward others during the Wicking II project period. Many of these necessitated police intervention and extensive follow-up with various authorities: medical reviews, hospital liaisons, police liaisons and liaisons with the government bureaucracies, as well as additional support and counselling for residents and staff during and after these incidents. These types of incidents created a lasting negative impression and had a profound influence over staff members' perception of the Wicking II program.

Such incidents can have a significant impact on a residential care site (affecting both residents and staff), much more than other, non-physically aggressive incidents. They provide a substantial drain on staff and management resources. Wintringham have advocated to government for many years that these types of incidents are not adequately resourced under the current government funding system. The under-resourcing of the support and management of these types of behaviours were a key driver for the commencement of the Wicking program.

Another area of tension created for project and facility management staff involved the lack of clarity in the transition process of Wicking II project participants into and out of the program. There were no clear markers for non-Wicking II staff to identify when a Wicking participant was no longer involved in the program. This uncertainty affected the admission of new participants into the Wicking program. In effect, the flexibility that allowed for pragmatic admission of Wicking residents led to newly referred non-Wicking residents being admitted to vacancies that were being held open for potential Wicking participants. This ultimately affected the number of participants recruited into the project.

Through a concerted effort involving additional support and good will from all staff and managers associated with the program and the residential care facility, Wicking II participants and non-Wicking II residents, for the most part, lived harmoniously. However, from the perspective of Wintringham management, it was agreed that the stand-alone facility model (of the Wicking I project) provided for a more focused support program for Wicking-type clients with far less 'collateral damage/impact' to neighbouring non-Wicking co-residents and staff.

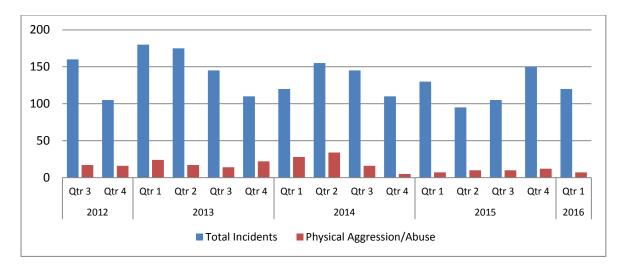


Figure 43 Number of reported incidents overall and incidents involving physical aggression at the site during the Wicking II project

# 5.5 The complex behaviour assessment tool

The Complex Behaviour Assessment Tool was a measure developed in 2012 as a result of an unmet need identified in the Wicking I project. It was developed to assess the behaviour support needs of people entering aged care services for the first time. Among myriad psychometric and generic behaviour assessments available to service providers, it became evident that none fully encompassed the behavioural traits characteristic of an ageing person experiencing multiple and complex needs. The impact of some of the behaviours that were not included in standard behaviour assessments was found to have a profound effect on the effectiveness of service delivery, as well as impacting the occupational health and safety of service personnel.

Therefore, Wintringham set about developing an assessment tool with the aim to identify all of the challenging behaviours commonly encountered in the delivery of residential aged care and community aged care services to older people experiencing homelessness or who were at risk of becoming homeless (Appendix C: The Complex Behaviour Assessment Tool).

A trial was undertaken to establish the effectiveness of the tool in determining the extent of behaviourally-driven care needs of newly referred Wintringham residential and community care clients. The assessment was completed for a number of clients prior to their admission. Through an iterative process, results and feedback were used to refine and improve the tool.

A significant benefit of this process was that the tool assisted in the development of individualised personal care plans for residents and clients who displayed behaviours of concern. The findings also informed the need for more thorough assessment, documented care plan strategies and determining whether interventions needed to be supplemented with additional expertise. Other benefits of the assessment tool included its use as:

- an intake screening method for new referrals using a whole of person approach
- an all-in-one tool that considered the full extent of the person's behaviour support needs and matched this with the capacity within the service to appropriately address these needs
- an assessment that could be easily administered by personnel, without requiring a medical practitioner or allied health professional
- assisting in the allocation of the most appropriate accommodation and support options;

- assisting in the development of individualised behaviour care plans and behaviour support strategies
- a point-in-time measure of behaviour support needs that could be repeated, to determine change over time
- a measure of the effectiveness of behaviour intervention strategies at reducing the frequency or severity of behaviours of concern.

The development of the Wintringham Challenging Behaviour Assessment Tool and its translation into practice was recognised by the Australian Aged Care Quality Agency as an initiative that demonstrated practice that went beyond minimum standards of aged care. As a result, the developers were invited to present a paper explaining the rationale and synthesis of tool to audiences at their Better Practice conferences throughout Australia.

The Wintringham Challenging Behaviour Assessment Tool will require further validation; however, it is anticipated that its use could ultimately fill a gap that currently exists to service providers in accurately assessing the support needs of older people living with complex neurobehavioural profiles. Armed with this knowledge, service providers will be able to evaluate their capacity to appropriately support the individual's needs, develop care plans to address these needs and evaluate the effectiveness of interventions at reducing the frequency or severity of challenging behaviour.

## 5.6 Economic outcomes

As discussed in the introduction of this report, older people who are at risk of, or experiencing, homelessness are more likely to be living with intellectual disabilities, ABIs, mental illnesses, drug and alcohol dependencies, and other forms of cognitive impairment. Without intensive support to access and sustain appropriate forms of housing, many of these people will continue to experience homelessness, and to have contact with other acute services in the community, including emergency departments, mental health CAT teams, community services and police. This only exacerbates the chaotic nature of their lives and compounds people's past experiences of trauma. It also increases risks to the community and placed pressures on already strained services and government budgets.<sup>167</sup>

Our calculations show that a potential cost saving of up to \$20,000 per participant to the health and justice departments is feasible from the program. The project outcomes clearly show that, for most clients, the Wicking I program was more cost effective. There was a faster improvement for clients within this model and it was also more cost effective.

## 5.7 Education and training outcomes

With a scarcity of research around the needs of staff working specifically with clients living with ARBI and the challenges they encounter, further enquiry into was considered beneficial. Due to increasing numbers of people living with an ARBI and an increasing ageing population accessing aged care services, more specialised services are required. Along with this, more specialised support and expertise is required for individuals and organisations working within this field, to gain a better understanding of the causes, limitations, issues and challenges of living with an ARBI and how to work more effectively with these individuals while improving the occupational health and safety of the people who provide their care.

Four factors may influence whether education and training result in staff behaviour change and improvements in client care: the quality of educational input; individual learner motivation; the nature, complexity and acceptability of the proposed change initiatives; and the receptivity of the care environment and its organisational context. Alongside learner characteristics such as learner motivation, the type or design of education and training plays a key role in the success or failure of the program. In addition, education programs need to consider factors that reinforce new knowledge, transfer knowledge into practice and sustain education.

Challenging behaviours can be complex, and consequently working in an interdisciplinary team was shown to be the most effective strategy. Sharing collective knowledge and expertise also minimised duplication of information and ensured that all factors were considered and addressed. To attain this, regular formal meetings and communications were required for the Wicking staff who were supporting participants on a day to day basis.

Education was provided to Wicking I and II support staff on how to deliver positive behaviour support to reduce the frequency or severity of challenging behaviours exhibited while focusing on improving the individual's quality of life. Staff were trained to interpret and understand the psychological issues and intervention techniques applicable to this population. They were also trained to implement these strategies in the development and delivery of individualised behaviour support plans and encouraged to implement positive change in their practice. The following key components of the training program were included:

- Applying the 'unmet needs' theory A person may exhibit behaviours when their needs are not met. Staff were encouraged to attempt to understand which individual unmet needs were contributing to their behaviour and support the participant to manage these needs in a more effective way.
- Using the ABCD model (Antecedents/or Activating Events > Behaviour > Consequences > Discuss and Debrief) The ABCD model focuses on triggers (antecedents) that precede behaviours, with the subsequent consequences reinforcing the behaviour. Staff were encouraged to determine antecedents that may have triggered the person's behaviour. Through the identifying of the ABCs, staff were guided on how to help target interventions aimed at reducing the antecedents or, in some instances, modifying the consequences.
- Considering The Biomedical Model Pathological changes to the brain can impair normal brain functions and cause behavioural symptoms. Staff were trained to understand that behaviours of concern often result from these changes in brain function and to understand that many of these behaviours are caused by the disease and are not an intentional or malicious act.
- Incorporating the participant's past history Staff were encouraged to adopt a more holistic view to the individual histories of the participant and how these can influence behaviours. These included taking into consideration their:
  - cultural backgrounds (e.g. customs, traditions, languages)
  - life histories (e.g. personal memories, homelessness, addictions, accomplishments, interests)
  - personality (e.g. introverted and quiet, loud and gregarious, sense of humour)
  - spirituality (e.g. religious beliefs, personal experiences)
  - values and beliefs (e.g. ability to trust others, acceptance of support, moral framework, respect for others)
  - social connections and support networks (e.g. roles within the community, homes)

- sexuality (e.g. desires instincts, preferences, feelings, beliefs)
- interests and hobbies (e.g. sports, crafts, music, cooking, gardening)
- extraordinary life events (e.g. positive and negative events, war, trauma, births, deaths)
- habits and routines (e.g. getting up early, going to bed late, using alcohol and drugs, being nomadic).
- Understanding the influence of carer interactions Staff were trained to understand that often the severity or frequency of behaviours of concern can be influenced by interactions between the person and their carers. Staff were trained to identify how their interactions provide a set of contextual cues and prompts that influence a participant's behavioural responses. Personal reflection was used to increase staff awareness of how their own biases and negative attributions could influence interactions with participants, particularly if they take the behaviour personally. Once an aspect of a staff member's communication style was identified as contributing negatively toward the person's behaviour, they were guided and supported to modify their responses in order to improve the outcome. This could include both non-verbal (e.g. language, facial expression, posture, tone of voice, eye contact) and verbal (e.g. judgemental language, message complexity and word complexity) aspects of communication. In summary, staff were supported in the following techniques:
  - Being mindful of your own reaction Know that your behaviour affects the behaviour of others. What you say or do in response to an individual's behaviour can affect whether the behaviour escalates or reduces.
  - Being mindful of your own prejudices or negative attributions Be aware of how your own life experiences may influence the way in which you respond to particular behaviours.
  - Maintaining rational emotional detachment Maintain control by not taking negative comments or actions personally and reacting instinctively or defensively, which may escalate the behaviour.
  - o Being attentive When people feel ignored, marginalised, or not cared for, they often act out, which may be expressed as a behaviour of concern.
  - Recognising your limits Being a professional doesn't mean that you can handle everything. Be aware of and use your support networks and backup systems.
  - Monitor, report and record Be actively involved in bringing about change in the process of behaviour management involves the establishment of routine and consistency through rigorous documentation practices.
  - Debriefing Be sure to debrief after any incident, as talking about it can help relieve
    the stress. These sessions not only support staff to discuss their concerns but also
    are important to inform the process of behaviour management planning.

## 5.8 Psychosocial outcomes

There were several limitations to this study, including small sample size, the heterogeneity of the participant group and the diversity of individualised interventions. To compensate for this design weakness, a conservative alpha-level was used to determine statistical significance. In view of this conservatism, the measured effect size was used to interpret whether a trend indicated clinical significance. Many of these determinations of clinical significance were corroborated by support staff through observation. Although the results should be interpreted with care, the data supported using a range of outcome measures, including HoNOS-ABI, to identify the complex needs to be targeted during the rehabilitation process. The findings of these studies demonstrated that the

intensive individualised programs delivered by the Wicking projects produced significant outcomes clinically and, in some instances, statistically in both functional outcomes and psychosocial quality of life in older adults.

The process of improving wellbeing included goal pursuit, goal adjustment, and optimisation of individual cognitive and physical strengths and avoidance of weaknesses. This highlights the importance of examining both independent and combined influences of ageing, cognitive and physical functioning and social aptitude and their influence on attaining positive psychosocial outcomes. The Wicking model demonstrates that gains that can be achieved through empowerment and adjustment, which offset the losses leading to positive outcomes.

The variability in positive outcomes was apparent, with the most significant outcome being demonstrated by a participant who transformed her life from a chaotic existence immersed in alcohol dependency leading to frequent assaults and hospitalisations to successfully maintaining independent housing and two years of sobriety as well as reconnecting with her family. For other participants, a successful outcome was achieved through the establishment of a degree of stabilisation in their lives. Examples included participants who took ownership and control of their addictions by managing their alcohol and cigarette intake by way of an alcohol program, reconnecting as a productive member of their community or successfully breaking the cycle of homelessness and disempowerment.

# 6 Wicking I and II project conclusions

Through this project, successful interventions and outcomes were achieved for older people experiencing homelessness while living with significant levels of cognitive impairment. Over ten years, the Wicking I and II projects have provided evidence that an intensive psychosocial support program can transition older people out of homelessness and into appropriate, long-term supported accommodation. We have shown that an individually tailored care and support program can improve life quality and wellbeing for older people living with an ARBI. Clinically significant reductions in average levels of alcohol consumption, depression, anxiety and behaviours of concern all resulted from participation in the Wicking program. Despite the high cost associated with the delivery of this intensive support program, comparative control group data and the monitoring of changes in emergency service usage throughout the project has demonstrated considerable cost-to-government savings.

This report analysed quantitative, psychometric, administrative and qualitative data collected from project participants and support staff. This chapter provides some concluding comments and recommendations in the areas of client outcomes, the Wicking project model and governance, and the service system.

## 6.1 Participant outcomes

The Wicking project has successfully helped participants reduce the frequency and impact of challenging behaviours, improved health and wellbeing, and decreased levels of hospitalisation and crisis and criminal justice service usage. The data suggests that some clients benefited more than others from Wicking project support; a small number of participants in each project did not engage effectively with the program and therefore continued to frequently engage with the emergency service system.

## 6.2 Service model and governance

Staff expressed a clear commitment to principles of the Wicking II project service model, and spoke particularly favourably about the flexibility and consistency of supports and behaviour management provided to its participants. In addition, the project has garnered high levels of recognition by such respected agencies as the Victorian Office of the Public Advocate, the National Ageing Research Institute, the Australian Aged Care Quality Agency and the International Aging and Society Common Ground community. Approval for capital grant funding has been received from the Australian Government Department of Ageing and Aged Care for the redevelopment of a property in Flemington to potentially accommodate a future Wicking III program.

A number of recommendations for the delivery model of a future program to support older people living with cognitive impairment and complex behaviour support needs, or a possible Wicking III program:

- 1. A 'stand-alone' model is recommended, as this has proven to be more economically viable than incorporating the program into a larger residential aged care facility with no compromise to psychosocial outcomes for its participants.
- 2. Participants are to be selected for eligibility along similar selection protocols as those employed for the Wicking I and II projects.

- 3. A dedicated case manager should be associated with the program, to assist with navigating through the complexity of need and issues faced by its participants.
- 4. A comprehensive neuropsychological assessment should be undertaken by all potential participants at the point of referral to the program. The outcomes of these assessments will help determine the cognitive strengths and weaknesses of participants, which will guide the development of individualised behaviour support plans.
- 5. Behaviour management planning using the ABCD method and a continuous improvement feedback process is recommended for participants in the program. This should always involve the participant as a contributor to the process, as well as key support personnel.
- 6. The psychosocial wellbeing of participants should be regularly measured and monitored throughout their participation in the program and the findings used in an iterative process of informing care practices and behaviour management planning.
- 7. Harm minimisation principles practised through an effectively administered alcohol and cigarette program creates a foundation for the establishment of mutually beneficial agreements between participants and facility staff. Participants are empowered through regaining control over their addiction and interventions are more effective through increased levels of rapport and trust.
- 8. Individualised, intensive structured activity programs are critical to the achieving successful outcomes for participants. Initially, providing approximately 25 hours of one-on-one activity programs to each participant each week is appropriate. This should be delivered by a dedicated team of well-trained and supported personnel. A schedule for the incremental decline in the number of program hours will vary according to individual circumstances; however, this generally reaches approximately eight hours per week after a six-month period.
- 9. The professional training of staff delivering the Wicking program empowers them to organise their thinking about complex, problematic behaviour and to develop proactive skills that focus on minimising the impact of these behaviours and building trusting, productive and respectful relationships with the participants. Opportunity for regular support, counselling and debriefing sessions should be made readily available to these staff.

## **6.3** Service costs

In summary, the cost of government services incurred by the 15 participants of the Wicking II project six months prior to enrolling in the project totalled \$452,617 – this value dropped to \$139,001 due to the overall reduction in services used six months after enrolment (Table 2). Therefore, the difference in cost pre- and post-enrolment was \$313,617 which equates to a cost saving of \$20,908 per participant (95%CI \$7,384–\$34,432), with the largest savings attributed to a reduction in hospital stays and ambulance usage.

## 6.4 Social justice

An increasing number of older Australians are finding it difficult to maintain secure and appropriate housing with their advancing years. There are numerous and varied pathways into homelessness for older Australians, whether they be homeless for the first time or caught in repeated cycles of homelessness, but very few programs offer long-term solutions out of homelessness. This is in part may be attributed to the high representation of people living with high and complex needs within this population. People who exhibit behaviours of unmet need can

often challenge care providers in the delivery of continued care, which in turn can lead to marginalisation, destitution and, all too often, premature death.

In the delivery of aged care services to Melbourne's homeless population over the past 27 years, Wintringham's model has evolved to meet a complex and often diverse set of care needs. Intervention and prevention strategies developed by generic aged care and homeless service agencies may not necessarily be the most effective for people who are elderly or experiencing premature ageing. Many research methodologies fail to capture the extent or intensity of issues pertaining to this population. All too often, the impact of stigmatisation, social isolation and long-term consequences of homelessness on the effectiveness of interventions and levels of engagement have been underestimated.

This population displays a high degree of heterogeneity with respect to the mechanisms and severity of their impairment, their symptomatology, general health and wellbeing. The manifestations of their cognitive impairment can be associated with complex behavioural profiles and debilitating symptoms. There is accumulating evidence to suggest that this population experience substantial morbidity, principally due to the risks associated with lifestyle practices or premature ageing. Therefore, risk reduction constitutes an important management goal. Individually tailored intensive support programs delivered by highly trained multidisciplinary teams, such as those trialled in the Wicking projects, reap rich health, social and economic benefits to its participants, their care providers and the social services sector.

The Wicking projects have improved the understanding of the support needs of older people living with a cognitive impairment while experiencing homelessness, and the influence that their disability and stigmatisation has on their ability to access appropriate and dignified care. The outcomes of this project can help service providers make positive changes in their practice, by establishing permanent pathways out of homelessness and delivering dignified options for long-term care.

# **Appendix A: The Wicking II Project Advisory Committee Members**

## Mr Bryan Lipmann AM

Chief Executive Officer, Wintringham & Wintringham Housing Limited PO Box 193, Flemington, Victoria 3031 Australia

## Professor Malcolm Hopwood MB BS MPM MD FRANZCP

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#### Dr Richard Rosewarne

Managing Director, Applied Aged Care Solutions Pty Ltd PO Box 4088, Victoria, 3103, Australia

## Hon. Robert Knowles AO

Former Member of the Victorian Parliament (1976 - 1999), Minister for Housing, Aged Care and for Health (1992-1999)

Commissioner, National Mental Health Commission

Former Member of the National Health and Hospital Reform Commission

Former Aged Care Complaints Commissioner.

Director, The Penington Institute

Director, The Royal Children's Hospital Melbourne

Director, Silver Chain/RDNS South Australia

#### Mrs Helen Small

General Manager Operations, Wintringham & Wintringham Housing Limited PO Box 193, Flemington, Victoria 3031 Australia.

# **Appendix B: Wicking II Project Evaluation Inventory**

**Wechsler Adult Intelligence Scale** – 4th Edition (**WAIS-IV**). <sup>170</sup> The WAIS-IV is a widely used measure of intellectual function that requires participants to provide verbal responses to questions, complete paper-and-pencil tasks and assemble blocks. <sup>171,172</sup> Domains of cognitive function assessment by the WAIS-IV include information processing, abstract verbal reasoning, arithmetic ability and visuo-constructional ability. Scores derived from the WAIS-IV that were used in the study include individual subtest scores from the following subtests: Picture Completion, Vocabulary, Digit Symbol Coding, Similarities, Block Design, Arithmetic, Matrix Reasoning, Digit Span and Information. Pro-rated Verbal IQ, pro-rated Performance IQ, and pro-rated Full-Scale IQ scores were also used.

**Wechsler Memory Scale** – 4th Edition (**WMS-IV**).<sup>173,174,175</sup> The WMS-IV is a widely used measure of memory function. The tasks require the participant to remember verbal and visual information, both immediately after its presentation and following a 30-minute delay. Subtests from the WMS-III used in the study include Logical Memory I and II (as measures of verbal memory function) and Visual Reproduction I and II (as measures of non-verbal memory function).

**Hopkins Verbal Learning Test (HVLT).** The HVLT requires the participant to learn a list of 12 words over three trials, to recall words from the list following a 30-minute delay, and to identify words that are on the list from a group of distracter items. The HVLT was used as a measure of verbal learning, with indices of performance including the total number of words recalled over three trials and the discrimination index from the recognition trial.

**Rey Complex Figure Test (RCFT).**<sup>177</sup> The RCFT requires participants to copy a complex figure and recall the figure three minutes after it was copied. The RCFT was used in the study as a measure of visuospatial ability, executive function and memory. Indices of performance include the score from the copy trial and recall trial.<sup>178</sup>

**Controlled Oral Word Association Test (COWAT).**<sup>179</sup> The COWAT requires participants to generate words beginning with letters 'F', 'A' and 'S' over a 60-second period. Indices of performance include number of correct words and number of errors. The task is a widely used a measure of executive functions, including idea generation and self-monitoring.

**Color Word Interference Task from the Delis Kaplan Executive Function System (DKEFS)**. <sup>180</sup> This task has four conditions: (1) naming colours; (2) reading colour names; (3) naming the colour of print of words, where the words are colour names (e.g. the participant is required to say 'green' when seeing the word 'red' written in green ink); and (4) switching between reading colour names and the colour of print. Scores from these four conditions were used as measures of focused attention and executive function.

**Colour Trials.** <sup>181</sup> This task has two conditions. The first requires participants to draw a line between ascending numbers scattered on a page that are in pink and yellow coloured circles. The second condition is identical to the first, except the participant is now also required to switch between colours (i.e. from a pink 1, to a yellow 2). The test is used as a measure of executive function.

Wechsler test of adult reading (WTAR). 182 The WTAR requires participants to read a list of

words. The test is a validated measure for estimating participants' pre-morbid level of intellectual function.

**Hospital Anxiety and Depression Scale (HADS)**. <sup>183</sup> The HADS is a 14-item scale containing two separately scored subscales of anxiety and depression. While the HADS was initially designed as a measure of anxiety and depression in non-psychiatric hospital settings, it has also been shown to be a valid and reliable measure in other settings with various populations. <sup>184</sup> It is relatively unaffected by concurrent physical illness. <sup>185</sup>

**Satisfaction with Life Scale (SWLS)**. <sup>186</sup> The SWLS is a global measure of life satisfaction. It consists of five items, and participants are required to respond on a 7-point Likert scale, with responses ranging from 'strongly agree' to 'strongly disagree'. The sensitivity of this test for use in people with ABI has been demonstrated. <sup>187</sup> The SWLS has adequate internal consistency and validity in research on aged populations and has been found to be responsive to physical activity in older adults. <sup>188,189</sup>

**Life Role Checklist**. <sup>190</sup> The Life Role Checklist is an 11-item scale reflecting participation in various occupational and social life roles. This instrument is the most widely accepted role assessment used by clinical occupational therapists <sup>191</sup> and has also been used successfully in research with older people. <sup>192</sup> In this study, individuals were asked to rate their current involvement in each life role.

**Neuropsychiatric Inventory Questionnaire (NPI-Q).** <sup>193</sup> The NPI-Q is a rapidly administered instrument that provides a reliable assessment of behavioural problems, psychotic symptoms, and depression. The information gained in the NPI-Q was also used to inform the participant's care plan, with useful non-pharmacologic interventions as well as adequate precautions to reduce the risk of harm and to minimise excess disability associated with treatable behavioural or mood disturbances. The NPI provides an assessment that can rule out iatrogenesis and treatable contributing causes to agitation. It is a useful tool in the assessment of the severity of the symptoms and the distress the symptoms cause the caregiver.

**Alcohol Use Disorders Identification Test (AUDIT)**<sup>194</sup> The AUDIT was developed by the World Health Organization to identify persons whose alcohol consumption has become hazardous or harmful to their health. It is a 10-item screening questionnaire with 3 questions on the amount and frequency of drinking, 3 questions on alcohol dependence, and 4 questions on problems caused by alcohol. The AUDIT is a validated tool and is currently being used in a variety of international research projects and epidemiological studies.

Overt Behaviour Scale (OBS). 195 The OBS is designed to clarify the types of observable challenging behaviours that can occur following ABI. It can help to show how behaviours may have changed over time and can inform decisions related to clinical interventions. The scale can also be used to measure the frequency of challenging behaviours and the impact that they have on people living and/or working with the client (including family members and service providers). The nine categories of behaviour that can be scored on this scale are: verbal aggression, physical aggression against objects, physical acts against self, physical aggression against other people, inappropriate sexual behaviour, perseveration/repetitive behaviour, wandering/absconding, inappropriate social behaviour and lack of initiation. This scale scores the severity, frequency and impact of each behaviour.

Health of the Nation Outcome Scales (HoNOS)-ABI. 196 The NoNOS-ABI is a modified version of a 12-item clinician-rated measure designed by The Royal College of Psychiatrists specifically for use in the assessment of consumer outcomes in mental health services. Ratings should be based on a thorough clinical assessment of the patient or client, with the clinician using a glossary that details the meaning of each point on the scale being rated. The HoNOS-ABI is a version specifically designed to best measure domains in functioning most relevant to the outcomes for individuals with ABI. This scale is designed to assess the neuropsychiatric sequelae of brain damage. The results demonstrate the proportion of participants that were rated as 'needing intervention', having 'minor symptoms', and having 'no symptoms' at the time of testing. The findings give further insight to the complexity of behavioural dysfunction and psychiatric symptomatology. In the present context, the HoNOS-ABI was used both as an outcomes assessment measure and as a case management indicator.

**Community Integration Questionnaire (CIQ)**. The CIQ provides accurate measurement of key concepts that define community integration, which are integral to ABI rehabilitation. <sup>197</sup> The CIQ is the most widely used and researched measure of community inclusion in rehabilitation literature. <sup>198,199,200,201,202</sup> It is a widely used tool measuring integration into the home and community following brain injury. Responses on the CIQ can be used to derive a total score and a score on each of three subscales (home integration, social integration and productivity) to determine the level of community integration experienced by the individual.

# **Appendix C: The Complex Behaviour Assessment Tool**



RES CP 28b

## COMPLEX BEHAVIOUR ASSESSMENT TOOL

Determining the behaviour support needs of clients exhibiting behaviours of unmet need

Determining the beneviour suppor				_
Conduct interview with the Client's case Client Name/DOB	mana	ger, I	NOK or rel	evant third party
Date of Interview	+			
Relationship to client/ Job title				
Site /Program Person providing information	_			
Interviewer				
GENERAL INFORMATION (Plea	ase tid Yes	k box) No	IUn-	COMMENTS
	163	140	known	COMMENTS
Guardianship Order				
Financial Administration Order				
Aboriginal or Torres Strait Islander				
Speaks a primary language other than English				Language: Interpreter Required? Yes / No
DIAGNOSED / CONFIRMED		TIN	DICATO	RS / SUSPECTED
(please tick box)				indicators if present but not diagnosed)
* □ Dementia				
*  ABI / ARBI				
☐ Post Traumatic Stress Disorde	r			
* □ Mental Illness				
☐ Personality Disorder				
☐ Intellectual Disability				
☐ Chronic Physical Illness or Disability				
*   Alcohol and Drug Addiction				
*   Memory Loss - Short term				
☐ Institutionalised in Childhood				
*   Previous Jail Term/s				
☐ Homelessness, or history of				
*   History of Physical Aggression				
*   Service Refusals / Evictions		$\perp$		
* □ Under 65 Years of Age				
Note: If client has two or more aste completed - please provide comme Comment:	erisks ent if y	s (*) /ou e	ticked a elect not	bove, the entire assessment should be to complete the assessment.
			_	

SOCIAL INTER	RACTION						
Activity		Frequer	псу				Score
☐ Positive engage family members		□none 0	□occas 1	sional	□frequent 2	□very frequent 3	
☐ Engages in hobbiinterests	bies or	□none 0	□occas 1	ional	□frequent 2	□very frequent 3	
Reads, newspap watches TV, liste radio/music		□none 0	□occas 1	sional	□frequent 2	□very frequent 3	
☐ Readily joins in g activities	group	□none 0	□occas 1	sional	□frequent 2	□very frequent 3	
<ul> <li>Attempts to help (including carers being asked</li> </ul>		□no 0	□occas 1	sional I	□frequent 2	□very frequent 3	
☐ Positive engage friends (includin etc)		□none 0	□occas 1	sional	□frequent 2	□very frequent 3	
☐ Enquires after th other people	e welfare of	□no 0	□occas 1	sional	□frequent 2	□very frequent 3	
						Social Sub score	
1. VERBAL	AGGRESS	SION					
☐ To self		□ То	others			☐ About others	
Behaviour	Severity			Frequ	ency		Score
□Threatens to damage objects or property	□mild □mo	oderate D	]severe 5	□осс	asional □freq 1 2	quent □veryfreq.	Severity X Freq.
□Threats- Targeted/ directed to a person or group	□mild □mo	oderate □ 4	Severe 5	□осс	asional □freq 1 2	quent □veryfreq. ? 3	
□Insults/ intimidating /Accusations	□mild □mo	oderate D	]severe 5	□осс	asional □freq 1 2	quent □veryfreq.	
□Profanities	□mild □mo	oderate 🗆	]severe 4	Посс	asional □freq 1 2	quent □veryfreq.	
						Sub Score Total	
Comment/Identifie	d Triggers:						

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2. PHYSIC	ALAGGRESSION			
□To others □To objects				
Behaviour	Severity	Frequency	Score	
☐ Spitting	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	Severity X Freq.	
☐ Body language / gestures	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3		
☐ Use of Weapons / equipment, mobility aids	□mild □moderate □severe 2 6 10	□occasional □frequent □veryfreq.  1 2 3		
Use of physical force	□mild □moderate □severe 5 10 20	□occasional □frequent □veryfreq.  1 2 3		
		Sub Score Total		

Other Forms of Physical Aggres	Other Forms of Physical Aggression (Please describe) / Further Information/Identified Triggers:		

3. SLEEP [	DISORDERS		
Behaviour	Severity	Frequency	Score
☐ Disrupted sleep/Insomnia	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.  1 2 3	Severity X Freq.
☐ Early riser	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.	
☐ Nocturnal/ night owl	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.  1 2 3	
□ Sleep Apnea	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
☐ Sleep Walks	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	

Comment:		

+			
4. INAPP	ROPRIATE SEXUAL BI	EHAVIOUR	
Behaviour	Severity	Frequency	Score
☐ Sexual - verbal	□mild □moderate □severe 2 3 4	$\square$ occasional $\square$ frequent $\square$ very freq.	Severity X Freq.
☐ Sexual- physical contact with others	□mild □moderate □severe 4 6 8	□occasional □frequent □veryfreq.  1 2 3	
☐ Sexual- physical contact with self	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq. 1 2 3	
☐ Sexual- literature/ images	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
☐ Unsafe sexual practice	□mild □moderate □severe 2 4 5	□occasional □frequent □veryfreq.	
		Sub Score Total	

Comment:	

5. REPETATIVE BEHAVIOUR			
Behaviour	Severity	Frequency	Score
☐ Verbal perseveration / repetition	□mild □moderate □severe 2 3 5	□occasional □frequent □veryfreq.  1 2 3	Severity X Freq.
☐ Physical e.g pacing	□mild □moderate □severe 1 2 3	$\square$ occasional $\square$ frequent $\square$ veryfreq.	
☐ Phone calls	□mild □moderate □severe 2 3 5	□occasional □frequent □veryfreq.  1 2 3	
☐ Persistent complaints/ demands	□mild □moderate □severe 2 3 5	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	

Other Forms of Repetitive Behaviour (Please describe) / Further Information / Identified Triggers:		

+

F*			
6. ENVIRO	ONMENTAL HAZARDS		
Behaviour	Severity	Frequency	Score
☐ Absconding	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	Severity X Freq.
☐ Entering un- safe or hazard - ous environment, eg: roads, or risking personal safety	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
☐ Invades others rooms or personal space	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	·

Other Forms of Wandering (Please describe) / Further Information:

7. SOCIALI	LY INAPPROPRIATE		
Behaviour	Severity	Frequency	Score
□Stealing /borrow without permission	□mild □moderate □severe 2 4 5	□occasional □frequent □veryfreq.  1 2 3	Severity X Freq
□ Hoarding	□mild □moderate □severe 2 4 8	□occasional □frequent □veryfreq.  1 2 3	
□ Vocalisations (non-sexual or aggressive)	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.  1 2 3	
□ Voyeurism	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
☐ Provoking conflict	□mild □moderate □severe 2 3 5	□occasional □frequent □veryfreq.  1 2 3	
☐ Urinating in public	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.	
☐ Defecating in public	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
☐ Defecating and smearing	□mild □moderate □severe 3 4 5	□occasional □frequent □veryfreq.  1 2 3	
☐ Habitual Spitting	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	

Comment/Identified Triggers:

8. FREQUENT EMERGENCY SERVICE USE				
Service	Frequency-per month			Score
☐ Hospital Emergency Department	□ 1-5 2	□ 5-10 6	□ <b>10+</b> 10	Freq.
☐ Ambulance	□ 1-5 2	□ 5-10 6	□ <b>10+</b> 10	
□ Police	□ 1-5 2	□ 5-10 6	□ <b>10+</b> 10	
			Sub Score Total	

Other (Please describe) / Further Information:

9. PSYCI	HIATRIC DISORDERS		
Disorder	Severity	Frequency	Score
☐ Self harm	□mild □moderate □severe 2 3 5	□occasional □frequent □veryfreq.	Severity X Freq.
☐ Suicide attempts / ideation	□mild □moderate □severe 2 4 8	□occasional □frequent □veryfreq. 1 2 3	
☐ Delusions/ hallucinations	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
□ Confabulations	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.	
□ Paranoia	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
☐ Grandiose ideations	□mild □moderate □severe 1 2 3	□occasional □frequent □veryfreq.  1 2 3	
☐ Depressed mood	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
☐ Anxious/ agitated	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	

Other Forms of Psychiatric Disorder (Please describe) / Further Information / Identified Triggers:			

Behaviour	Severity	Frequency	Score
☐ Excessive Alcohol consumption	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	Severity X Freq.
☐ Other drug consumption	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
□ Unsafe IV drug use	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
□ Ingestion or inhalation of unsafe materials	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
☐ Misuse of Prescription medication	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
□ Unsafe Smoking	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
□ Excessive Gambling	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
□ Butt stooping	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	
ner Forms of Add	liction (Please describe) / Furthe	r Information:	

11. NE	GLECT		
Behaviour	Severity	Frequency	Score
☐ Physical Environment	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq. 1 2 3	Severity X Freq.
☐ Personal hygiene	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.	
☐ Social Isolation –lack of initiation/ motivation	□mild □moderate □severe 2 3 4	□occasional □frequent □veryfreq. 1 2 3	
☐ Non compliance – refusal of treatment	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
☐ Refusal/ Neglect to use aids/ equipment	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
☐ Dietary/ nutritional	□mild □moderate □severe 2 4 6	□occasional □frequent □veryfreq.  1 2 3	
		Sub Score Total	

Other Forms of Neglect (Please describe) / Further Information / Identified Triggers:	

## **SCORING**

Social Interaction Sub score	
Category Sub scores	TOTALS
Verbal Aggression	
Physical Aggression	
Sleep Disorders	
Inappropriate Sexual Behaviour	
Repetitive Behaviour	
Wandering/Missing Person	
7. Socially Inappropriate	
Frequent Emergency Service Use	
Psychiatric Disorders	
10. Alcohol and Other Addictions	
11.Neglect	
Total Score	

SUB SCORES GREATER THAN 12 WITHIN EACH CATEGORY INDICATE THE PRESENCE OF A SIGNIFICANT BEHAVIOUR OF UNMET NEED – Refer to the site/program manager for further consideration.

A TOTAL SCORE GREATER THAN 100 INDICATES THE PRESENCE OF MULITPLE BEHAVIOURS OF UNMET NEED – Refer to the site/program manager for further consideration

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