

# Wintringham



## **THE WICKING PROJECT**

OLDER PEOPLE WITH ACQUIRED BRAIN INJURY & ASSOCIATED  
COMPLEX BEHAVIOURS: A PSYCHOSOCIAL MODEL OF CARE

### **Final Report**

Dr. Alice Rota-Bartelink

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Dedicated to the memory of Mr Glenn Woods and Mr Michael Nicholas.



## Executive Summary

### **The Wicking Project. Older People with Acquired Brain Injury and Associated Complex Behaviours: A Psychosocial Model of Care.**

Currently Australia has a well developed aged care service system. Comprehensive aged, health and social care services are generally effective in delivering appropriate care and support to the majority of the aged population. Yet despite the richness of services available, there are still groups of people living in the community who are not gaining access to these services or not utilising them to their full potential to meet individual needs. There are also some people for whom these services lack the specialised skills or resources required to adequately address these needs. Homeless persons living with multiple diagnoses constitute a particularly vulnerable subgroup within the community and present with extremely complex service needs<sup>1</sup>.

2

Wintringham is a not-for-profit welfare company that has been providing aged care services specifically targeted at elderly homeless men and women (50 years and older) for the past 22 years. Throughout this time, the company has never lost sight of this target population and continues to provide services that are appropriate to the complexity of need exhibited by this group of frail and vulnerable Australians. The demographic of Wintringham clients reflect a population of people who have faced a significant degree of personal and financial hardship throughout their lives, usually accompanied by significant health, social and housing crises. Premature aging, substance abuse disorders and undiagnosed mental illness are commonplace. The Wintringham Model of Care has evolved from the specialised support requirements presented in the delivery of appropriate care to this client population<sup>2</sup>.

Alcohol problems among older people are increasingly common. Years of continued excessive drinking can lead to Alcohol Related Brain Injury (ARBI). ARBI rarely occurs in isolation with a significant proportion of sufferers having both a substance abuse disorder (alcohol and/or other drugs) and a mental illness, or age-related dementia and other forms of acquired brain injury. A person living with an ARBI most commonly presents with damage to the frontal lobes of their brain characterised by poor decision making and increased impulsivity<sup>3,4</sup>. This manifests with the person readily engaging in inappropriate or high-risk behaviours in the absence of being able to regulate these behaviours. The behaviours are undertaken despite the individual having previously demonstrated an awareness of the negative consequences of these actions. It is very common for older people with multiple needs to be particularly unwilling to seek and utilise specialist or mainstream services.

People living with alcohol-related brain injury receive less empathy and often attract more judgemental attitudes in the public view than people living with age-related dementias. People living with an ARBI are often preoccupied with activities directed toward the procurement of alcohol. In the absence of adequate funds, they often resort to whatever means possible in order to access alcohol including criminal activity, stand-over tactics, begging or selling-on possessions of any significant value. Unfortunately, for many the cycle of homelessness becomes entrenched.

Although, in the provision of appropriate support the goal is to utilise the least restrictive intervention possible, there are times when a community-based setting can not meet the therapeutic needs of an older person living with an ARBI. In these situations, highly specialised treatment can only be made available in a residential care setting or, in instances of extremely violent behaviour, in an institutional locked ward.

The Wicking Project centred on a research trial that investigated the effectiveness of a specialised model of residential care in improving the life quality and wellbeing of individuals with extremely challenging behaviours resulting from an ARBI. This action research was exploratory in nature incorporating both qualitative and quantitative outcome measures to determine the effect of interventions. Changes were measured using depression, anxiety, aggression, psychosocial behavioural and life satisfaction and 'quality of life' assessment tools.

Fourteen volunteer participants living with an ARBI and history of homelessness were allocated to either an intervention (Household Participant) or control (Community Control) group. Seven intervention participants took part in a supported residential trial. The remaining participants continued to reside within the community without project intervention beyond their participation in appointed assessments.

The residential trial 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). These initiatives were supported by a team of highly trained and skilled personnel including neuropsychological case management. The key elements of the model included intensive recreation and behaviour modification programs and individualised drinking and smoking programs. A social justice approach was used to build community bonds, a sense of belonging, and new life skills and confidence.

3

### **Structured Activity/Recreation Program**

The Wicking Recreation Program was characterised by a process that assisted participants to 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 the removal of these barriers through inventive and innovative approaches designed not to impact significantly on enjoyment rewards. Wicking Model participants were initially very resistant to participating in structured activity programs. However, through a persistent and skilled approach, levels of 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.

### **Behaviour Modification**

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, 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 achieving a better understanding of 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.

### **Alcohol & Cigarette Program**

The provision of alcohol in the form of a controlled drinking program had a significant positive influence on the behavioural manifestations of Wicking Model participants. It provided respite from the daily hardship arising from not knowing when and how the next drink or cigarette was to be acquired. 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.

### Other Outcomes

Economic modelling demonstrated that compared with a group of older people living with an ARBI within the community, Wicking Model participants presented considerable cost-to-government savings of \$30 per person per day. Statistically significant reductions were measured in the levels of anxiety, depression and total amount of alcohol consumed (down by 62%). Levels of productivity were also shown to have increased significantly. Nearly all outcome measures and life quality indicators experienced positive change within the intervention group who participated in The Wicking Model of Care.

Following the project, the majority of Wicking Model participants have continued to live in a less intensive supported residential environment (“step down” transition) and successfully maintained gains as best as they are able, further achieving life markers such as positive relationships and personal goals. Particular elements that formed the continuum of care in the Wicking Model of Care were integral to a successful integration into mainstream residential care including: the alcohol and cigarette program; financial administration and successful transfer and implementation of behaviour management strategies; individual structured activity programs and the adopted philosophical approach to service delivery.

4

The results have shown that older people living with an ARBI and coexisting behaviour disorders can significantly benefit and sustain outcomes from a six month, intensive residential care model that is multi-modal and holistic in its approach. Significant improvements in the mental health of Wicking Model participants suggest that interventions aimed at improving older adults’ perceptions of freedom and personal choice with regard to their leisure experiences, maintaining optimal health, and increasing opportunities to foster feelings of belonging and relatedness with others, could protect against the progression of mental ill health.

Based on the success of the Wicking Project this specialised model has shown potential to deliver an appropriate, cost-effective and dignified care solution to older people living with an ARBI and challenging behaviour. The model could potentially be promoted as an intensive transitional care strategy designed to facilitate a step-down transition from a congested hospital or crisis driven service system into long-term residential aged care solutions.

# Table of Contents

|                                                                          |    |
|--------------------------------------------------------------------------|----|
| <b>Executive Summary</b>                                                 | 3  |
| <b>Table of Contents</b>                                                 | 7  |
| <b>List of Figures</b>                                                   | 9  |
| <b>List of Tables</b>                                                    | 10 |
| <b>Definitions and Acronyms</b>                                          | 11 |
| <b>1 Introduction</b>                                                    | 14 |
| 1.1 The Wicking Project Hypotheses and Aims                              | 16 |
| <b>2 Phase One – Project Start Up</b>                                    | 18 |
| 2.1 Incubation Stage                                                     | 18 |
| 2.2 Investigative Stage                                                  | 18 |
| 2.2.1 The Wintringham Model of Care                                      | 18 |
| 2.2.2 Older People, Homelessness, Dementia & Alcohol Abuse               | 21 |
| 2.2.3 Overseas ARBI Services Overview                                    | 32 |
| <b>3 Phase Two – Trialling The Wicking Model of Care: Project Design</b> | 33 |
| 3.1 Methodology                                                          | 33 |
| 3.1.1 Participant Recruitment                                            | 33 |
| 3.2 The Wicking Project Participants                                     | 34 |
| 3.2.1 Pre-participatory Demographics                                     | 36 |
| 3.3 The Wicking Trial Communication Strategy                             | 43 |
| 3.4 Governance of The Wicking Project                                    | 44 |
| 3.5 The Wicking Project Model of Care – Overview                         | 45 |
| <b>4 Phase Three – Project Evaluation</b>                                | 47 |
| 4.1 Methodology                                                          | 47 |
| 4.1.1 Evaluation Inventory                                               | 48 |
| 4.1.2 Statistical Analyses                                               | 50 |
| <b>5 Wicking Project Outcomes</b>                                        | 52 |
| 5.1 Outcome Summary                                                      | 52 |
| <b>5.2 Major Learning Outcomes – Operational</b>                         | 56 |
| 5.2.1 Transitional Model                                                 | 56 |
| 5.2.2 Targeted Structured Activity Program                               | 56 |
| 5.2.3 Dual Diagnoses                                                     | 57 |
| 5.2.4 Cognition, ARBI & Challenging Behaviours                           | 59 |
| 5.2.5 Emergency Planning                                                 | 60 |
| 5.2.6 Service Coordination                                               | 61 |
| 5.2.7 Drinking & Smoking Culture                                         | 62 |
| 5.2.8 Harm Minimisation                                                  | 65 |
| 5.2.9 Participant Life Cycles                                            | 68 |
| 5.2.10 Other Drugs                                                       | 69 |
| 5.2.11 Neuropsychological Involvement                                    | 71 |
| 5.2.12 Participant Selection Protocol                                    | 72 |
| 5.2.13 Disability Support Services                                       | 73 |
| 5.2.14 Aged Care Assessment Service                                      | 73 |
| 5.2.15 Capability & Capacity                                             | 74 |

|            |                                                               |     |
|------------|---------------------------------------------------------------|-----|
| 5.2.16     | Gender Specificity & Sexuality                                | 75  |
| 5.2.17     | Staff Training & Support                                      | 75  |
| 5.2.18     | Individual Care Plans & Specialist Case Management            | 76  |
| 5.2.19     | The Spiral of Negativity                                      | 77  |
| 5.2.20     | Project Partnerships                                          | 78  |
| 5.2.21     | The Wicking House Rules                                       | 78  |
| <b>5.3</b> | <b>Memorable Wicking Moments</b>                              | 79  |
| 5.3.1      | Wicking BBQs                                                  | 79  |
| 5.3.2      | Christmas 2008                                                | 79  |
| 5.3.3      | Radio Interview                                               | 79  |
| 5.3.4      | The Wicking Holiday                                           | 79  |
| 5.3.5      | Music Therapy?                                                | 80  |
| <b>5.4</b> | <b>Measurement Outcomes</b>                                   | 81  |
| 5.4.1      | Analysis                                                      | 81  |
| 5.4.2      | Life Roles                                                    | 82  |
| 5.4.3      | Anxiety                                                       | 83  |
| 5.4.4      | Depression                                                    | 84  |
| 5.4.5      | Alcohol Use Disorder                                          | 85  |
| 5.4.6      | Alcohol Consumption                                           | 86  |
| 5.4.7      | Productivity                                                  | 87  |
| 5.4.8      | Cigarette Consumption                                         | 88  |
| 5.4.9      | Satisfaction with Life                                        | 89  |
| 5.4.10     | Neuropsychiatric Behaviour                                    | 90  |
| 5.4.11     | Overt Behaviour                                               | 90  |
| 5.4.12     | Health of the Nation Outcome Scales                           | 92  |
| 5.4.13     | Physical Health                                               | 93  |
| 5.4.14     | Subjective Wellbeing                                          | 95  |
| 5.4.15     | Behavioural Changes over Time                                 | 96  |
| 5.4.16     | Relationship Between Variables                                | 99  |
| 5.4.17     | Neuropsychological Outcomes                                   | 99  |
| <b>6</b>   | <b>Discussion</b>                                             | 101 |
| 6.1        | Social exclusion                                              | 102 |
| 6.2        | Service Integration                                           | 103 |
| 6.2.1      | Research                                                      | 104 |
| 6.2.2      | Regulatory Processes                                          | 104 |
| 6.2.3      | Resource Allocation Processes                                 | 105 |
| 6.2.4      | Recognition and Utilisation of Skills & Expertise             | 105 |
| 6.2.5      | Specialist Services                                           | 105 |
| 6.3        | Structural Factors                                            | 106 |
| <b>7</b>   | <b>Conclusion</b>                                             | 109 |
|            | <b>Appendix A – The Malcolm</b>                               | 111 |
|            | <b>Appendix B – Wicking Project Participant Consent</b>       | 116 |
|            | <b>Appendix C – Example of Drinking &amp; Smoking Program</b> | 122 |
|            | <b>Appendix D – Wicking Project Correlation Findings</b>      | 124 |
| <b>8</b>   | <b>References</b>                                             | 125 |



## Stories

|                     |    |
|---------------------|----|
| The Story of Gordon | 26 |
| The Story of Trevor | 47 |
| The Story of Frank  | 50 |
| The Story of Gary   | 55 |
| The Story of Wayne  | 58 |
| The Story of Jack   | 61 |
| The Story of Mark   | 70 |

## List of Figures

|           |                                                            |     |
|-----------|------------------------------------------------------------|-----|
| Figure 1  | Source of Referral for The Wicking Project Participants    | 35  |
| Figure 2  | Participant Demographic Data                               | 36  |
| Figure 3  | Pre-participatory Living Arrangements and Support Networks | 37  |
| Figure 4  | Pre-participatory Education and Employment History         | 38  |
| Figure 5  | Pre-participatory Crime and Emergency Service Interactions | 38  |
| Figure 6  | Neuropsychological and Community Integration Findings      | 39  |
| Figure 7  | Reported Addictive Behaviour Exhibited                     | 40  |
| Figure 8  | Reported Incidence of Challenging Behaviour Exhibited      | 41  |
| Figure 9  | Reported Mental Health Problems                            | 42  |
| Figure 10 | Reported Incidence of Physical Health Problems             | 43  |
| Figure 11 | The Wicking Project Organisational Chart                   | 45  |
| Figure 12 | Complexity of Support Services Available                   | 62  |
| Figure 13 | The Downward Spiral of Negativity                          | 77  |
| Figure 14 | The Wicking House Rules.                                   | 78  |
| Figure 15 | The Average Change in Outcome Scores                       | 82  |
| Figure 16 | Changes in the Number of Valued Life Roles                 | 83  |
| Figure 17 | Hospital Anxiety & Depression Scale – Anxiety              | 84  |
| Figure 18 | Hospital Anxiety & Depression Scale – Depression           | 85  |
| Figure 19 | Alcohol Use Disorders Identification Test                  | 86  |
| Figure 20 | The Number of Drinks Consumed per Day                      | 87  |
| Figure 21 | The Community Integration Questionnaire                    | 88  |
| Figure 22 | Number of Cigarettes Smoked per Day                        | 89  |
| Figure 23 | Changes in Life Satisfaction over Time                     | 90  |
| Figure 24 | Changes in Neuropsychiatric Behaviour over Time            | 91  |
| Figure 25 | Changes in Overt Behaviour over Time                       | 92  |
| Figure 26 | Changes in Health of the Nation Outcome Scales over Time   | 93  |
| Figure 27 | Changes in General Health Conditions over Time             | 94  |
| Figure 28 | Graded Subjective Descriptors of Life Quality over Time.   | 95  |
| Figure 29 | Frequency of Incidents of Challenging Behaviours Overall   | 96  |
| Figure 30 | Frequency of Observed Intoxications                        | 97  |
| Figure 31 | Frequency of Incidents of Verbal Aggression                | 98  |
| Figure 32 | Frequency of Incidents of Physical Violence                | 98  |
| Figure 33 | Clinician Rated Neurological Change                        | 100 |

## List of Tables

|         |                                                                                                                                                            |     |
|---------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Table 1 | Physical Health Problems of an Older Melbourne Homelessness Population Excluding Substance Abuse Disorders (based on respondents' reports) <sup>48</sup> . | 23  |
| Table 2 | Differences in Cognitive and Behavioural Changes Associated with Alcohol Related Brain Injury versus Alzheimer's Disease.                                  | 29  |
| Table 3 | Identification Checklist for Wicking Project Participants                                                                                                  | 35  |
| Table 4 | Cost to Government Comparisons for Service Delivery to Wicking Model Participants Compared with Community Control Participants                             | 54  |
| Table 5 | Percentage of Older Australians at Various Levels of Risk of Long-term Harm Through the Consumption of Alcohol 2007                                        | 87  |
| Table 6 | Mean Number of Cigarettes Smoked per Week, by Age and Sex, Australia, 2007.                                                                                | 88  |
| Table 7 | Example of a Wicking Model Participant's Drinking Program                                                                                                  | 122 |

## Definitions and Acronyms

**ABI** Acquired Brain Injury refers to any type of brain damage that occurs after birth.

**ACAT/S** Aged Care Assessment Team/Service which is funded by the Commonwealth Government.

**ACFI** Aged Care Funding Instrument developed by the Commonwealth Government.

**Aged** The terms 'elderly' and 'aged' are usually taken to mean people aged over 65 years of age. However the terms can apply to younger people within specific target groups with special support needs such as the long-term homeless and Indigenous people. It has been demonstrated that homeless populations have a higher rate of serious morbidity and premature mortality compared to the general population, with Westernised countries reporting an average age of death between 42 and 52 years. Therefore, it has been recommended that the age of 50+ be used to define older homelessness.

**Aged Care** Support and services provided to the aged population by a large number of Government programs (Commonwealth, State/Territory and local) as well as programs/support from the community and voluntary sectors, the private for-profit sector and the private not-for-profit sector.

**ARBI** Alcohol Related Brain Injury/Damage is a term used to describe a condition whereby individuals are affected by significant levels of cognitive impairment and behavioural disorder occurring as a result of long-term alcohol abuse.

**ATSI** Aboriginal or Torres Strait Islander

**CBDATS** Community Brain Disorders Assessment and Treatment Service which is funded by the State Government.

**Challenging Behaviour** Generally described as behaviour that, either directly or indirectly, seriously disrupts or affects the lives or routines of other people or services.

**COAG** Council of Australian Governments

**Cognition** The mental process of knowing, including aspects such as awareness, 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.

**Community Control Participants** Wicking Project Participants who continued to live in the community and engaging with their established service providers without additional project intervention beyond their participation in three monthly assessments and outcome measures.

**Dementia** Describes a syndrome associated with a range of diseases characterised by a progressive impairment of brain functions, including cognitive skills, memory, perception, personality and language.

**Dual Diagnosis** A term used to describe people who have a major mental health diagnosis and who is also substance dependent.

**Executive Functioning** Includes 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.

**HARP** Hospital Admission Risk Program (HARP) which is funded by The Victorian State Government. Provides specialised client-centred medical care and care coordination in the community through an integrated response of hospital and community services.

**Homeless** The absence of housing and the marginalisation from social networks and community services.

**Korsakoff Amnesic Syndrome** Clinical condition associated with long-term alcohol abuse and Thiamine deficiency. Characterised by intact immediate memory, a profound difficulty learning new information, poor recall of recent events, confabulation and lack of spontaneity.

**Learning Impairment / Disability** A general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities.

**MACNI** Multiple and Complex Needs Initiative which is funded by the State Government

**OOH** Office of Housing. Provider of the State Government's Department of Human Services housing service, including emergency and transitional accommodation, long term rental housing, private rental and home ownership assistance.

**Psychosocial** The psychological development or adjustment of an individual in relation to his or her social environment.

**RACF** Registered Aged Care Facility which is funded by the Federal Government.

**RDNS-HPP** Royal District Nursing Services Homeless Persons Program which is jointly funded by the State Governments (Through the Supported Accommodation Assistance Program) and Aged Community and Mental Health (ACMH).

**Stigma** The shame or disgrace attached to something regarded as socially unacceptable.

**SRS** Supported Residential Services which receive no Government funding.

**Thiamine** Vitamin B1

**SSDT Act** Severe Substance Dependence Treatment Act (2010)

**The Wicking Project** A research trial funded by The JO & JR Wicking Trust titled: *Older People with Acquired Brain Injury and Associated Complex Behaviours: A Psychosocial Model of Care That Supports Long-Term Residential Care Needs (The Wicking Project) 2006 - 2010*. These funds were administered by ANZ Trustees LTD.

**The Wicking Project Model of Care** A care model developed during the Wicking Project to manage the difficult behaviours of participants living with an ARBI and assist in their transition into Wintringham residential care services.

**The Wicking Household** The home in which Wicking Project Model of Care participants were housed.

**Wintringham** An organisation that provides aged care services targeted specifically at elderly homeless men and women. Services include low and high care residential facilities, an extensive choice of housing and support options and Community Care Packages.

# 1 Introduction

Older people living with an acquired brain injury and challenging behaviour tend to be shuffled between homeless service providers, housing support services, emergency services, correctional services and mental health services, all of which cannot provide appropriate long-term residential care solutions. By the nature of its client population, the Wintringham service delivery model has evolved to incorporate flexible, tolerant and non-judgemental strategies to address a myriad of unique and diverse care needs. Many of these needs occur as a direct result of premature aging reflected in the high and early incidence of chronic illnesses, but more significantly, as a result of complex behaviours associated with long-term mental illness, alcohol-related brain damage and homelessness.

Wintringham's non-conventional approach to service delivery has enabled it to grow while continuing to successfully support the needs of people for whom all other avenues of care have failed; people with little to no family; people with little to no financial means; and people for whom 'safety and trust' are intangible concepts – people who currently do not fit neatly into any existing category of care. Over 20 years of operation, a unique model of care has evolved from the foundation of Wintringham services. This model has proven successful in enabling people from diverse and sometimes abhorrent backgrounds to live together in harmony whilst receiving care appropriate to their widely varied needs.

11

The gap in the provision of highly specialised supported accommodation for older people exhibiting challenging behaviour as a result of an Alcohol Related Brain Injury (ARBI) was the driving force behind this project. The Wicking Grant has enabled Wintringham to address a gap in not only its own service delivery but in the Australian welfare industry. Through the development of a specialised residential care model we aim to move one step closer to providing appropriate support to one of the most needing yet highly marginalised group of people.

The Wicking Model of Care was therefore built on the base of the existing Wintringham model and then intensified in order to address an increased complexity of need. The project aimed to make a significant contribution to improving the quality and appropriateness of care and support options available to this often forgotten and neglected group of people and to enable them to live out their final years with dignity.

The project, fully titled '*Older People with 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 was managed by ANZ Trustees. The Wicking Project was advised by a highly regarded and esteemed committee of representatives from academic and key service industries.

The funding of this project by the JO & JR Wicking Trust has provided the opportunity to develop and trial a novel model of specialised care, the outcomes of which will be used to inform social, health and aged care industries. This research would otherwise not have been possible due to the high costs associated with the delivery of such an intensive service model and the existing barriers in the current service system restricting access to appropriate aged care services. Orchestrated and implemented by Wintringham, independence from the Government sector has allowed this project to effectively mitigate departmental jurisdictional boundaries, budgetary constraints, varying eligibility criteria and bureaucratic red tape that could otherwise have impeded its implementation.

The focus of The Wicking Project reflects the population of older people living with a history of homelessness, financial disadvantage and complex care needs as a result of an alcohol-related brain injury (ARBI). While the path to alcohol addiction begins with the voluntary act of consuming alcohol, over time a person's ability to choose not to do so becomes compromised, and the seeking



and consuming of alcohol becomes compulsive. This behaviour results largely from the effects of prolonged drug exposure on brain functioning. Prolonged exposure affects multiple brain functions, including those involved in reward and motivation, learning and memory, and inhibitory control over behaviour.

The Wicking project was developed with purpose to influence Government and policy makers with a view to changing systemic responses to the needs of older people living with an ARBI. This will be achieved by increasing the awareness among policy makers of the gaps that continue to exist within the current service system and the multiple points of breakdown in service coordination and cooperation. These failings come despite a Council of Australian Governments (COAG) commitment in 2006 to establish a flagship national initiative directed at providing more seamless and coordinated health and community services for people with a severe mental illness and complex needs who are most at risk of falling through the gaps in the system.

12

The group of people that were supposedly targeted by this Government initiative were those with persistent symptoms and significant disability, who have lost social or family support networks and rely extensively on multiple health and community services for assistance to maintain their lives within the community<sup>5</sup>. Unfortunately, many in this group continue to fall 'through the cracks' bouncing haphazardly from service to service while their health slowly and painstakingly deteriorates. The Wicking Project served to provide a net for this group.

The Wicking 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 what factors will increase the likelihood that positive, individual and systemic changes can occur for this population. Phase 2 consisted of a demonstration pilot fully titled: *Older People with Acquired Brain Injury and Associated Complex Behaviours*, 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 based on an eighteen-month demonstration pilot. The third phase (Phase 3) titled: *An Evaluation of a Psychosocial Model of Care That Supports Long-term Residential Care Needs* involved the evaluation of The Wicking Trial and the establishment of project outcomes.

The Wicking Specialised Model of Residential Care was developed in consultation with Government, homeless and community care service providers, Wintringham Staff, older homeless clients and expert advisors. Through an effective communication strategy, The Wicking Project has provided an information platform from which other service providers can develop or improve their service delivery responses to older people living with an acquired brain injury.

## 1.1 The Wicking Project Hypotheses and Aims

The two hypotheses of The Wicking Project were:

That the domains of life quality and wellbeing will improve among individuals living with behavioural disturbances resulting from alcohol related brain injury through their participation in The Wicking Model of Care; and

That The Wicking Project outcome will determine the appropriateness and the sustainability of The Wicking Model and its potential to transfer to other residential aged care environments.

The specific project aims were:

**The Wicking Model of Care:** To develop a model of care that would:

- a Minimise potential harms presented to participants through the reduction of risky/inappropriate lifestyle practices usually undertaken through day to day activities;
- b Provide therapeutic interventions designed to stabilise and de-escalate behaviours and interrupt the downward spiral imposed by increasingly disruptive behaviour;
- c Provide a therapeutic environment conducive for older people living with an ARBI to commence recovery from the impact of physical, psychological and emotional trauma, and pain experienced from abuse and neglect;
- d Establish a partnership with the participant that allows their individual needs, goals and ambitions to be met;
- e Promote development by building participants' capacity to sustain positive relationships with others; and
- f Work towards improved connection and integration of the participant into the community.

**Evaluation:** To provide evidence that would make a significant contribution to improving the quality of life for people living with severe behavioural disturbances and to close an identified gap in the current service system.

**Communication:** The Wicking Project Communication Strategy aimed to influence Government and policy makers with a view to changing systemic responses to the needs of older people with an acquired brain injury. This was achieved by increasing the awareness among policy makers of the gaps that exist within the current service system in delivering appropriately specialised services to meet the needs of this population, and by offering a solution in the form of a validated model of long-term care and support. More specific aims of the communication strategy included:

- a Increasing awareness of care and referral options available to older people living with an acquired brain injury;
- b Increasing awareness of the signs and symptoms associated with acquired brain injury to facilitate the identification of affected individuals by aged care service providers;
- c Providing an information platform from which other service providers can develop appropriate service delivery responses to older people among their own service users suffering from acquired brain injury.

## 2

## Phase One – Project Start Up

## 2.1

**Incubation Stage**

A Wicking Trust Incubation Initiative Grant supported the undertaking of a literature review to inform design of a JO & JR Wicking Major Strategic Grant project (The Wicking Project). Investigations scoped literature that reviewed national and international services providing specialised supported accommodation, care and support to older people living with acquired brain injury resulting from alcohol abuse. This resulted in the publication of a detailed literature review which was published and distributed widely to service providers and policy makers nationally and internationally. The purpose of this literature review was to provide a theoretical framework for this study and to inform the aged care sector of the range of services available in Victoria and inadequacies within the current system. As well as highlighting aspects of successful designs, strategies and interventions which were noted for inclusion in the Wicking Project.

14

## 2.2

**Investigative Stage**

The investigative phase led to the production of an investigative report examining the existing Wintringham service delivery model. A series of focus group meetings were used to inform this report. Focus meetings established an understanding of the Wintringham model from a number of perspectives including frontline staff, management, representative of the Board of Directors, the Chief Executive Officer and key external service providers including Aged Care Assessment Service (ACAS), Royal District Nursing Service Homeless Persons Program (RDNS-HPP), Homeless Services, Mental Health Services, Local Government community services etc. This approach helped to identify inconsistencies in service delivery, staff training and supervision needs, and other possible barriers to effective service delivery, evaluations, and the achievement of desired goals. A report detailing the Wintringham model of care can be accessed via the website [www.wintringham.org.au/research](http://www.wintringham.org.au/research).

The second element of the first phase involved the design and development of The Wicking Model of Care and methodology for The Wicking Trial.

## 2.2.1

**The Wintringham Model of Care**

Wintringham is a not-for-profit welfare company that provides aged care services specifically targeted at elderly homeless men and women (50 years and older). The company currently employs in excess of 400 staff to deliver services to approximately 1200 clients each night through a range of programs including residential aged care facilities, rooming houses, independent living units, community aged care packages including the extended aged care at home packages and outreach services.

By the nature of its clients, Wintringham's service delivery model has evolved to incorporate flexible, tolerant and non-judgemental strategies to address a myriad of unique and diverse care needs while still promoting maximum independence and access to the community. Many of these needs result from premature aging which is reflected in the high and early incidence of chronic illnesses, but more significantly, the need to address the complexity of behaviour associated with long-term, poorly managed mental illness, alcohol related brain damage and extended periods of homelessness.

The task of documenting the current Wintringham model of residential care presented some unexpected challenges the most significant of which was the difficulty in qualifying exactly what differentiated the Wintringham model from other homeless and mainstream aged care services. Yet the very characteristics that made Wintringham services effective made them more difficult to describe and evaluate. It therefore proved difficult to elucidate the true philosophy and ethical principles underlying the culture of the company and its staff as they delivered care and support focused on the individual needs of clients. In documenting this model, care was needed to do justice to these concepts through the use of language that has of recent years been trivialised through overuse and exploitation.

Subsequent investigations identified that the principal defining feature of the Wintringham model was its adaptability. The care model employed to support one individual resident may not necessarily be considered unique among mainstream residential services but the model employed for one resident may differ significantly to that implemented to support the next resident. The model that successfully supported one resident one week may be completely different to that required by the same resident the following week.

15

The model is constantly evolving and changing. This necessitated the contribution of committed, innovative, flexible and well trained staff and the utilisation of thorough documentation practices. The key to Wintringham's success therefore is attributed to Wintringham's ability and willingness to modify and adapt its approach in response to individuals' wants and needs and a tolerance of the accompanying risks.

The Wintringham model was initially developed in the late 1980s from a melding of aged care, social justice and homeless service principles. Rather than having been strategically developed in preparation for the commencement of the service, the Wintringham model evolved gradually through an adaptive process driven by the demand created by the special care needs of the client population. Rather than creating a model to which the residents had to adapt, the model adapted and continues to evolve to meet the needs of each individual.

This often involved the trialling and implementing of a variety of care strategies. Some of these strategies were adapted from models of care used by existing services at the time, but most were developed through trial and error by staff who were encouraged to be inventive, flexible and open minded. Always, the strategies were grounded on the fundamental principle of social justice.

The essential difference between the mainstream aged care service system and Wintringham lay in the history of the client population. The fact that many residents entered Wintringham from institutional backgrounds compared with people who entered mainstream aged care from relatively independent lifestyles in their own homes, goes some way to differentiate the two client groups. As a result many of the new Wintringham residents almost immediately began to display skills that had remained unused for many years. In contrast, many people who entered mainstream aged care services began to relinquish skills that they had previously maintained.

As changes, particularly in the mainstream aged care system have been made, these differences have become less evident today, yet fundamental population differences still remain. The average Wintringham client is male, in his sixties and originating from a working class background. Mainstream aged care clients are predominantly female, in their eighties and from a middle class background. Decision makers at all levels, including politicians and policy makers, often have limited opportunity to learn of the reality and plight of people such as those supported by Wintringham. The company, since its inception has tirelessly advocated for the right of this client population to be recognised at all levels of Government.

The newer Wintringham client population, although less likely to have come from an institutional background, present with an increased frequency of issues relating to mental illness, drug and alcohol addictions and complex care needs. This shift has placed increased demand on the flexibility and adaptability of the Wintringham model of care and the need for an input of knowledge from external specialist service providers.

Because Wintringham has maintained its single focus on providing services to older homeless people, this has enabled specialised skills to develop within its staff. There is a strong culture focussed on staff well-being and opportunities for advancement within the company. Wintringham staff have a strong commitment to pursuing quality outcomes for frail, older, homeless men and women which are strongly guided by the fundamental principle of social justice. This is consistently practiced at all levels of the company and underpins the practice of an empowered model of staff self-management. Service program teams are given the autonomy to independently self-regulate the delivery of their services within framework directed by company policy.

A unique model of care has evolved from the foundation of Wintringham services. This model has proven successful in enabling people from diverse and sometimes abhorrent backgrounds to live together in harmony whilst receiving care appropriate to their widely varied needs.

Since its inception, Wintringham has successfully cared for older people living with an alcohol-related brain injury (ARBI) within an aged care setting, yet despite this level of specialisation, there have been some individuals presenting with severely affected behaviours that have challenged Wintringham's capacity to meet the resource requirements to adequately support their highly intensive needs. These people characteristically display aggressive, violent or antisocial behaviours which have left them ostracised and alienated from society and denied access to appropriate support services.

This experience is evidenced by a 2003 case study that profiled the success of an intensive support trial provided to a Wintringham resident living with an advanced ARBI. The case study mentioned provided evidence that Wintringham staff possessed the skills and expertise required to successfully deliver appropriate care at this level, but lacked the funding to maintain this support for any length of time within a mainstream funded aged care environment (Appendix A). The Wicking Project has provided the opportunity to develop and trial a specialised model of residential care to provide appropriate care and support to this group of people.

## 2.2.2

### Older People, Homelessness, Dementia & Alcohol Abuse

#### 2.2.2.1

##### Past and Present

In Australia, up until the mid to late 1980s, frail elderly homeless men and women lived and died in homeless persons' night shelters. Three large homeless persons' night shelters operated in Melbourne at the time and all had large numbers of frail elderly residents in need of hostel or nursing home level care. For a variety of reasons, some prejudicial, workers at these homeless service centers found it extremely difficult to place frail elderly homeless residents in mainstream aged care residential services. As a result aged men and women were forced to live in environments that were frequently violent, intimidating and totally ill-equipped to provide appropriate aged care services.

The night shelters have since closed down or been substantially altered following the redevelopment of Melbourne's Homeless Accommodation services in the mid to late 1980s<sup>6</sup>. Today there are a



number of Federal and State funded programs available to homeless people. However, despite the existence of these programs, community service providers continue to be frustrated with the lack in availability of long-term specialised supported accommodation for older people.

Historically, support for the elderly homeless with complex needs has been managed, with varying levels of success in an uncoordinated, ad hoc manner by a range of service systems including; medical and emergency, social, residential, aged care, justice, homeless and mental health service providers. After examining the plight of older homeless people, Purdon (1991) observed that older homeless people were, in general, “*chronically homeless and unlikely to be able to make a transition to independent living, and (will) require a range of supported accommodation options*”. It was also noted that elderly women, Indigenous Australians, and people from non English speaking backgrounds were particularly disadvantaged<sup>7, 8</sup>.

Working with elderly homeless people presents particular problems for service delivery, in part because of the often noted incidence of premature ageing, combined with a general reluctance to accept services. Homeless people often have poor interpersonal skills and are suspicious of people they don't know, including service providers, and it generally takes a great deal of time to build up a relationship of trust. Areas where homeless people may require additional support include personal care, leisure activities, overcoming or managing alcohol and/or drug dependency and medical and dental issues<sup>9</sup>. These individuals can experience difficulty negotiating complex systems due to cognitive or behavioural problems.

Over the last two decades, in Australian and international literature, there has been increasing use of terms ‘complex needs’<sup>10</sup> or clients with ‘highly complex behaviours’<sup>11</sup>. However these terms more often are used to refer to people whose needs and behaviours present significant, sometimes intractable challenges to all health, human service and criminal justice systems. Representing a very small proportion of the population but requiring considerable resources, a significant proportion of these people also experience homelessness from time to time<sup>12</sup>.

In the literature, there is no generally agreed definition of ‘challenging behaviour’<sup>13, 14</sup>. It has been described as behaviour ranging from the extreme; dangerous or life threatening to less severe behaviour that is distressing and disturbing to the person or to others. Severity is therefore subjectively determined by numerous factors associated with the actual behaviour, the context in which the behaviour occurs and the perceptions of the behaviour by others. Although the proportion of older people who manifest with severely challenging behaviour is limited, the impact they have on society can be immense with repercussions extending to multiple service systems. Within this population, challenging behaviour can be of such intensity that it poses a significant risk to the health of the individual and to that of others around them.

Frequently, older people living with an overlay of challenging behaviour possess a complexity of care needs that require a high level of residential care and support, yet they are often alienated from most community-based residential care options. Discrimination occurring at the entry level of many aged care services forces these people to seek alternative modes of accommodation, most of which are inappropriate and many that are detrimental to personal safety and wellbeing. All too often, with no-one to advocate or support them, this results in a continuing cycle of increasing behavioural disturbance, hospital admissions, restrictive interventions and frequently, premature death occurs often as a consequence of violence.

## 2.2.2.2

## Homelessness &amp; Health

It has been demonstrated that homeless populations have a higher rate of serious morbidity and premature mortality compared to the general population, with westernised countries reporting an average age of death between 42 and 52 years<sup>15,16,17</sup>. Ill-health can be considered to be both a cause and an effect of homelessness. People with pre-existing chronic or acute illnesses may find that the illness can contribute toward becoming homeless and then these illnesses may be further exacerbated, or new illnesses develop as a result of the lifestyle and living conditions that a homeless person may be exposed to. A major international research review identified that homeless people are 3–4 times more likely to die than the general population<sup>18</sup>. While elderly homeless persons have a greater risk of dying than their housed counterparts, the most glaring discrepancies in mortality ratios are seen in the younger and middle-aged (35 to 54 years of age) cohorts.

The Royal District Nursing Service – Homeless Person Program (RDNS HPP) report, *It Can Be Done – Health Care for People who are Homeless*, found that in reference to homeless people as consumers of health and other support services: “... their lives are characterised by trauma, uncertainty and fear. They have experienced negative interactions with the public health system, may lack confidence to negotiate the complexities of the system, and frequently experience embarrassment in relation to their circumstances and the potential judgement of those service providers they come in contact with. As a result they may be suspicious, frightened, or lacking in motivation to seek health care.” (p.8)<sup>19</sup>.

The experience of homelessness not only causes illness but it can exacerbate pre-existing health issues to critical levels. These issues are then often addressed in a partial or fragmented way, especially for those experiencing frequent and lengthy episodes of homelessness. In a Melbourne study it was found that almost half respondents (n=56) reported that their main source of medical assistance was received from the local public hospital<sup>55</sup>. Seventy-eight percent of all respondents reported having health problems prior to becoming homeless, of which one third (30%) stated that their physical health problems contributed significantly to their homelessness. Premature aging is frequently associated with premature admission into residential care, extended stays in hospital, and the requirement of a higher level of support<sup>20</sup>.

| Physical Health Problems  | Men  | Women | Total  |      |
|---------------------------|------|-------|--------|------|
|                           | %    | %     | Number | %    |
| Musculo-skeletal 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  |

**Table 1** Physical Health Problems of an Older Melbourne Homelessness Population Excluding Substance Abuse Disorders (based on respondents' reports)<sup>55</sup>.

## 2.2.2.3

## Alcohol Related Brain Injury

The consumption of alcohol is intrinsic to the Australian culture, yet it has been demonstrated that beyond the effect of public awareness campaigns such as 'drink-driving', Australians have a limited understanding of the extent of alcohol-related harm through its chronic abuse<sup>21</sup>. About a third of older people with drinking problems develop them for the first time in later life. Bereavement, physical ill-health, difficulty getting around and social isolation can lead to boredom and depression. With the changes in life roles that often accompany retirement there may be less pressure on an older person to regulate their drinking due to diminished responsibility for maintaining family support and accountability for having to go to work each day.

The misuse of alcohol among older people is often described as a 'hidden' or 'neglected' area of research<sup>22</sup>. Throughout the world alcohol problems among older people are increasingly common<sup>23</sup>. It has been found that a significant number of people over 65 years of age exceed recommended drinking limits<sup>24</sup>. The frequency of under-diagnosis of alcohol problems in the older population is considered to be significant, principally due to the awareness of the effects of long-term abuse being low among frontline workers in health and social care<sup>25, 61</sup>.

19

Alcohol is more toxic in the ageing body because of age-related changes in the way it is metabolised, distributed and eliminated<sup>26</sup>. This can lead to central and peripheral nervous system effects even at lower levels of intake. Organs such as the brain and liver are particularly vulnerable. To complicate the issue, there is an emerging ageing population who have experienced long-term exposure to illicit drugs and are therefore more likely to be affected by drug-induced ill-health and brain injuries.

Long term alcohol abuse is often found to be associated with cognitive impairment caused by alcohol related brain damage (ARBI)<sup>27</sup>. ARBI is caused by a combination of Thiamine (vitamin B1) deficiency, general cerebral shrinkage (secondary to alcohol consumption), and a range of other insults to the brain including repeated head injury or assault<sup>60</sup>. The process of metabolising alcohol increases the metabolic demand for Thiamine, which plays an important role in ensuring that the brain receives a steady supply of sugar. In addition, alcohol dependence also decreases the absorption of Thiamine from the gut. And because alcohol-dependent people are prone to food deprivation, their nutritional status is generally poor, increasing their vulnerability to ARBI.

A number of factors have been shown to influence the extent to which, and how rapidly, alcohol affects the brain. These include: how often a person drinks and the quantities consumed; the age at which they first began drinking; how long they have been drinking; their socioeconomic background; whether the person has a family history of alcoholism; and their general health status<sup>28</sup>.

A brain injury can cause symptoms similar to psychosis and dementia as well as eliciting significant problems with impulse control, social skills and self-awareness. 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>29</sup>. Behavioural disorders can also result from two common syndromes associated with long-term alcohol abuse and ARBI. They are the Korsakoff Amnesic Syndrome and the Adaptive Behaviour Syndrome:

The Korsakoff Amnesic Syndrome is characterised by intact immediate memory, a profound difficulty learning new information, poor recall of recent events, confabulation and lack of spontaneity<sup>30</sup>.

The Adaptive Behaviour Syndrome is characterised by poor planning and organisation, concrete and inflexible thinking, lack of insight, inappropriate behaviour and a lack of self-criticism<sup>30</sup>.

The behavioural characteristics commonly associated with ARBI have been shown to differ from that of age-related dementias particularly with regard to social skills and social interactions resulting in a completely different set of complex care needs<sup>31,32</sup>. People living with an ARBI present with behavioural disturbances that can mostly be attributed to an impairment of the frontal lobes of the brain. The diversity of symptoms can include impairments in executive functioning, ability to learn (learning difficulty), thought processing and emotional regulation. Although general measures of intelligence may not reveal performance deficits in the early stages of ARBI<sup>33</sup>, detailed neuropsychological testing can demonstrate deficits in cognitive flexibility, problem solving, verbal and non-verbal abstraction, visuo-motor co-ordination, learning, conditioning, and memory<sup>33,34,35,36</sup>.

The relationship between alcohol and aggression is not straightforward. Harmful and hazardous drinking increases risks of becoming both a victim and a perpetrator of violence. The risk of becoming a perpetrator is increased as alcohol reduces self-control, the ability to process information and to detect risky situations together with increases in impulsivity. This makes some individuals more likely resort to violence as a problem solving strategy. In victims, alcohol reduces the ability to detect risk and exert physical control over an imminent threat of harm.

Associations between aggressive behaviour and alcohol have been documented, particularly in relation to consuming large amounts of alcohol on the one occasion or 'binge drinking', drinking to intoxication and also to the frequency of drinking<sup>37</sup>. It has also been shown that men who exhibit aggressive behaviour when intoxicated are more likely to have experienced high levels of aggression as children and experienced life-long patterns of impulsive, violent aggression<sup>38,39</sup>.

Cognitive and behavioural problems are complicated by physical conditions relating to long-term alcohol misuse. People living with an ARBI are more likely to suffer from mental health problems that may precede the injury or occur as a result of major disruption to their health, functional capacity and lifestyle following the injury<sup>40</sup>.

Treatment for ARBI can include a combination of interventions including cognitive/behavioural remediation, psychotherapy, and pharmacotherapy<sup>29</sup>. Current research suggests that psychosocial intervention treatments may potentially yield better outcomes in addition to being less expensive and having fewer side effects than medication; however they rely on a greater degree of expertise and training of support staff as well as careful planning and execution of care plans<sup>41</sup>. Behaviour management therapy involves a process of understanding what reinforces and sustains maladaptive behaviours and designing methods or teaching skills that reduce or eliminate them<sup>42</sup>.

More than 2,500 Australians are treated for ARBI every year, yet the exact prevalence of ARBI is difficult to ascertain as it often remains undiagnosed due to difficulties in differentiating between ARBI and other age-related conditions and dementia<sup>43</sup>. It is also probable that people with long-term alcohol addiction and their families conceal the condition because of the attached stigma.

#### 2.2.2.4

### ARBI versus Alzheimer's & Other Aged-Related Dementias

#### 1.2.2.4.1

### Physiology of Alzheimer's Disease

Alzheimer's disease (AD) is an irreversible, progressive brain disorder that occurs gradually and results in memory loss, unusual behaviour, personality changes, and a decline in thinking abilities. These losses are related to the death of brain cells and the breakdown of the connections between them. The course of this disease varies from person to person, as does the rate of decline. AD is the

most common cause of dementia among people aged 65 and older. On average, AD patients live for 8 to 10 years after they are diagnosed; however, the disease can last for up to 20 years.

AD destroys neurons in parts of the brain controlling memory, especially the hippocampus (a structure deep in the brain that helps code memories). As nerve cells in the hippocampus stop functioning properly, short-term memory fails, and often, the person's ability to do familiar tasks begins to decline. AD also attacks the cerebral cortex. The greatest damage occurs in areas of the cerebral cortex responsible for functions such as language and reasoning. Here, AD begins to take away language skills and change a person's judgement. Personality changes also occur; emotional outbursts and disturbing behaviour, such as wandering and agitation, appear and can happen more and more often as the disease runs its course. AD advances by stages, from early, mild forgetfulness to severe dementia. Dementia is the loss of mental function. In most people with AD, symptoms first appear after age 60. The earliest symptoms often include loss of recent memory, faulty judgement, and changes in personality. Often, people in the initial stages of AD think less clearly and forget the names of familiar people and common objects. Later in the disease, they may forget how to do simple tasks like washing their hands. Eventually, people with AD lose all reasoning abilities and become dependent on other people for their everyday care. Finally, the disease becomes so debilitating that patients are bedridden and likely to develop coexisting illnesses. Most commonly, people with AD die from pneumonia.

#### 1.2.2.4.2

##### Physiology of ARBI

Alcohol related brain injury presents as a more global deterioration in intellectual function with memory not being specifically affected<sup>44</sup>. Sufferers can present in their early thirties although the more common age for presentation is in the fifth, sixth and seventh decades. The World Health Organisation describes dementia as: *"a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement"*<sup>45</sup>. In line with conventional definitions, ARBI may not be considered a true form of dementia, in that some degree of recovery is possible<sup>46</sup>.

In a younger person at an early stage of ARBI, there is evidence of improved brain functioning and possibly recovery of some damaged brain cells<sup>47</sup>. Behavioural problems may be reduced or reversed if the person abstains from alcohol, their diet is improved and vitamins, especially thiamine, are replaced<sup>48</sup>. For people recovering from alcohol-related brain damage (ARBI) however, there is evidence of improved cognitive functioning over the first two weeks of abstinence but conflicting evidence as to the possibility of further improvement over longer periods of time<sup>22</sup> especially in an older age group. Although varying degrees of recovery from a brain injury can occur, there is typically some degree of permanent impairment.

Korsakoff Amnesic Syndrome causes the destruction of certain areas of the brain, where changes in memory are the main symptom<sup>44</sup>. There is evidence that the frontal lobes are particularly vulnerable to alcohol related damage, and the brain changes in these areas are most prominent as the long-term drinker ages. As previously discussed, damage to the frontal lobes causes disinhibition, loss of planning, decline in executive functions and a blithe disregard for the consequences of their behaviour, decreasing the likelihood of a long-term drinker being able to maintain extended periods of sobriety. Most presentations of ARBI are somewhere along the spectrum between moderate cognitive impairment and the more severe conditions of Korsakoff Syndrome and global dementia.



## 1.2.2.4.3

## Contrasting Care Needs

Unlike other forms of dementia, which are common only in elderly people, anyone (regardless of age) who is a regular heavy drinker is at risk of succumbing to alcohol related dementia with the additional contributory factors of: age; chronicity; pattern of alcohol use and nutritional intake. Therefore, there is a clear aetiology. Rather than the slowly progressive decline in cognitive functioning that occurs in Alzheimer's disease, the decline that occurs in ARBI is irregular and correlated with the severity of drinking behaviour. This distinction may have implications for the prognosis and treatment of patients, as evidence suggests that alcohol related brain injury is less progressive than Alzheimer's disease and potentially partially reversible.

As a broad generalisation, compared with people living with Alzheimer's disease, a cohort of older people living with cognitive and behavioural effects of ARBI are; predominantly male, relatively young, physically stronger, more aggressive, of working class background, have experienced long-term personal and financial hardship, have little to no family contact, continue to experience repeated episodes of acute intoxication and commonly associate with people of inauspicious character. Whereas, people living with Alzheimer's disease are predominantly female, older, physically weaker, of middle-class background and tend to maintain social connectedness with family and friends.

22

Approximately one-third of people living with Alzheimer's disease exhibit the signs and symptoms of aggressiveness, the severity and frequency of which are correlated with the severity of their dementia<sup>49</sup>. However, physical frailty and immobility are often limiting factors to the level of risk incurred by staff and others through these behaviours. Compare this to an ambulant man in his mid-fifties to mid-sixties, living with an ARBI, who has experienced a lifetime exposure to violence and aggression. This person would pose a significantly greater risk to the safety of others when exhibiting aggressive behaviour, particularly whilst intoxicated. Even the most effective behaviour management care plan is proven ineffective when a person is intoxicated and the tendency toward aggressive behaviour is amplified in both its volatility and its intensity.

The diagnostic criteria used currently for alcohol related brain injury is based almost exclusively on clinical judgement such as that provided by neuropsychological assessment. Few guidelines are available to assist clinicians and researchers in distinguishing alcohol related brain injury from other causes of dementia, despite differences in neuropsychological profiles (see Table 1 below). Because the prognosis and needs of a person living with alcohol related brain injury can differ significantly from those of other forms of dementia, differentiation between the two conditions is important to the long-term management of these people's needs and selection of the most appropriate residential placement.

| ARBI                                                                   | ALZHEIMER'S                                                                         |
|------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <b>Key Features</b>                                                    |                                                                                     |
| Cognitive deficits tend to stabilise with abstinence from alcohol.     | Worsening of short-term memory, especially for details of recent events.            |
| Unable to learn – confabulation, executive & visuospatial dysfunction. | Language difficulties such as problems finding the right word & with comprehension. |
| Slowed & poorly controlled motor function.                             | Increasing disorientation with respect to geographical location & time.             |
| Apathy, disinhibition & impulsive behaviours common.                   | Problems with motivation & initiating tasks.                                        |

| <b>Memory &amp; Learning</b>                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Characterised by a prominent inability to learn new material.</p> <p>Unable to learn new information but retains old skills (retrograde amnesia with temporal gradient).</p> <p>Executive dysfunction &amp; inability to self-monitor leads to confabulation 'filling the gaps'. Interviewing is vital to confirm details if this diagnosis is suspected.</p> | <p>Difficulties learning or storing new information.</p> <p>Visual &amp; verbal memory loss – forgetting conversations, requests and directions.</p> <p>Difficulty storing new memories (beyond thirty minutes) but retain past memories &amp; emotionally and personally meaningful events.</p> <p>Memory is not prompted by reminders but strong associations can sometimes help (for example, linking a word to an action or familiar event).</p>                                                                                                                           |
| <b>Attention</b>                                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <p>Alertness is impaired although registration of auditory material is usually acceptable.</p> <p>Normal immediate auditory attention (such as remembering a phone number).</p> <p>Alertness &amp; orientation to time &amp; place often impaired – distractible.</p>                                                                                            | <p>Not all people suffer from attentional problems in the early stages.</p> <p>Alertness &amp; sustained attention are not usually affected until later stages.</p> <p>Difficulty with divided attention (doing two things at once), selective attention (knowing what to attend to) &amp; shifting attention (from one task to another).</p> <p>Less able to hold auditory information in attentional store (like phone numbers).</p>                                                                                                                                         |
| <b>Language Skills</b>                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <p>Language functioning generally remains intact.</p> <p>Reading, writing &amp; comprehension retained although verbal fluency may decline.</p>                                                                                                                                                                                                                  | <p>Use of language is usually appropriate, but sentences may remain unfinished or the person might get stuck trying to find a word.</p> <p>Commonly suffer from difficulties finding words unless prompted.</p> <p>Circular speech patterns – talking around topic, can't think of the word, speech seems 'empty' of meaning.</p> <p>Verbal fluency may be affected with restricted quantity &amp;/or rate observed.</p> <p>Writing &amp; reading are often impaired.</p> <p>Comprehension sometimes affected early on but the basic principles of language remain intact.</p> |
| <b>Verbal Skills</b>                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <p>Reduced abstract &amp; logical reasoning.</p> <p>Impaired abstract verbal reasoning but well-learned verbal knowledge preserved.</p>                                                                                                                                                                                                                          | <p>No difficulties usually apparent in early stages.</p> <p>Well-learned verbal knowledge usually preserved in early stages.</p> <p>Verbal processing such as reasoning ability may reduce in later stages.</p>                                                                                                                                                                                                                                                                                                                                                                |

|                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Visuospatial &amp; Nonverbal Skills</b>                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <p>Many people with an ARBI have impaired visuospatial function.</p> <p>Visuospatial impairment common as seen with non-verbal tests like Clock Drawing Test.</p>                                                                                            | <p>Difficulties apparent in early stages, such as making things or putting things together &amp; drawing (especially copying) becomes difficult.</p> <p>Difficulties using maps – may become disoriented even in familiar places.</p> <p>Difficulties copying a demonstrated action &amp; with sequencing unfamiliar processes.</p> <p>Increasing difficulties carrying out familiar tasks in the correct order.</p>                                                                                                                                                                                                                         |
| <b>Information Processing Speed</b>                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <p>Psychomotor skills can be impaired.</p> <p>Motor function &amp; control are usually impaired due to cerebellar atrophy.</p>                                                                                                                               | <p>Slow to respond to questions and to carry out tasks, caused by slower processing speeds.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Executive or Higher Order Functioning</b>                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <p>Executive deficits are widespread.</p> <p>Lack of mental flexibility &amp; impaired problem solving – decreased spontaneity.</p> <p>Difficulties with planning &amp; organisation including poor judgement.</p>                                           | <p>Usually only mild difficulties apparent in early stages.</p> <p>Retain self-awareness &amp; insight initially.</p> <p>Increasing difficulties in reasoning, abstraction, judgement &amp; mental flexibility.</p> <p>Difficulty understanding information unless with examples or demonstrations.</p> <p>Difficulty moving onto a new topic in conversation, adapting to a new situation or following movie storylines.</p>                                                                                                                                                                                                                |
| <b>Behaviour &amp; Personality</b>                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <p>Behaviour &amp; personality change are relatively common.</p> <p>Apathy and its symptoms including reduced affect, initiative &amp; social withdrawal.</p> <p>Agitation, anxiety &amp;/or depression may occur -also disinhibition &amp; impulsivity.</p> | <p>Behaviour change not typically an early sign although behaviour may change to compensate for cognitive changes.</p> <p>Embarrassment, depression, apathy, social withdrawal, reduced appetite, poor sleep &amp; reduced spontaneous speech may occur as a reaction to brain changes.</p> <p>May become emotional, irritable, frustrated or angry about their symptoms.</p> <p>Memory problems can lead to suspicion &amp; paranoia as they try to make sense of their confusion (for example, may think a misplaced item is stolen).</p> <p>Personality changes, social interactions &amp; daily functioning are affected by disease.</p> |

**Table 2** Differences in Cognitive and Behavioural Changes Associated with Alcohol Related Brain Injury versus Alzheimer’s Disease. Reproduced with permission from Alzheimer’s Australia<sup>50</sup>.

## 2.2.2.5

## Homelessness &amp; Alcohol Abuse

The relationship of alcohol and drug use to homelessness is interactive and iterative in that it can be both a cause and an effect of homelessness<sup>51</sup>. The incidence of alcohol abuse among the homeless population is considerably higher than in the general population<sup>52, 53, 54</sup>. The Wintringham experience shows that many older homeless people present with long-term, well entrenched patterns of drinking, a history of multiple failed attempts at sobriety and, very often, varying degrees of alcohol related brain injury.

In a Melbourne study that interviewed 125 older homeless people (aged 50 years and over) and their caseworkers, forty-three percent of respondents reported having issues with alcohol (48% men and 28% women) with nearly one half of the men admitting to heavy drinking or alcohol dependence<sup>55, 56</sup>. It was also found that those who had been previously homeless (60%) were more likely than those who had not previously been homeless (32%) to report problems with alcohol. The case worker's reports show that there was significant under-reporting of alcohol problems. They reported that 77% of men and 44% of women had alcohol problems that were either evident or suspected. These results support the findings of another Melbourne study in which 75% of older clients using Salvation Army Services were reported to have some degree of cognitive impairment; the majority being alcohol related brain injury and fifty percent were reported to have had ongoing chronic drug and alcohol abuse issues<sup>57</sup>.

The presence of dementia is highly prevalent within the older homeless population and is usually multi-factorial in aetiology. Research has found that approximately 50% of homeless service users (58% of homeless men and 42% of homeless women) have a history of traumatic brain injury<sup>58</sup>. The most common of which were shown to be acquired brain injuries (ABI) arising from long-term exposure to the harmful levels of alcohol intoxication and/or head trauma. People with multiple diagnosis including mental illness, substance abuse and ABI often find it difficult to access appropriate services. These individuals may have trouble negotiating complex systems due to cognitive or behavioural problems. Even with help, barriers exist. The multiply diagnosed are often unable to get assistance because of their co-morbid diagnosis. When a multiply diagnosed patient is homeless these barriers are magnified. Commonly accompanying these injuries is an overlay of challenging behaviours that may further alienate the individual from social inclusion and accessing mainstream aged care and support.

The incidence of ARBI is far wider reaching than the confines of the homeless population, with the prevalence of problem drinking in nursing homes being reported as high as 49 percent in some studies<sup>59</sup>. The condition is frequently misdiagnosed and very often misunderstood by health professionals, service providers and care givers<sup>60, 61</sup>. Because a person living with an ARBI characteristically experiences behavioural changes such as being more impulsive and unable to appropriately link actions to consequences, it is very unlikely that in the advanced stages of the disease a person is capable of maintaining prolonged periods of sobriety. Continued heavy drinking subsequently leads to further brain injury, deterioration in brain functions and increasingly challenging needs.

People living with an ARBI do not fit neatly into one division of service provision, making appropriate service delivery problematic. Unfortunately, some service providers and professionals regard ARBI as 'not their problem' due to the complexity of the condition. At an agency level, fiscal restraints can limit the intensity and duration of treatment. The gap in the provision of specialised supported accommodation and the lack of effective information available to the aged care industry

on the specialised support needs of this population is a driving force behind the development of this project.

### **The Story of Gordon (Aged 51 years)**

Gordon was referred to The Wicking Project by his case manager due to tenuous tenancy and an inadequacy of appropriate support. Gordon had resided in 'temporary accommodation' for four years since his discharge from hospital after sustaining a severe traumatic brain injury from a motor vehicle accident. Extensive pursuits for appropriate housing had previously proven unsuccessful. Gordon's case manager held serious concerns over the appropriateness of Gordon's relationship with his neighbours, suspecting exploitation. Although Gordon had guardianship and financial administration orders and a care support package in place, his case manager felt he required more specialised and intensive care and support.

When interviewers first met Gordon at his home he presented as a friendly but cautious man. His constant companion was a little Jack Russel Terrier. Although Gordon had two living siblings, he had no contact with them. Gordon reported being abused both sexually and physically from a young age and began drinking heavily after leaving home at approximately 14 years of age. Gordon reported consuming approximately one cask of wine and twenty cigarettes per day and marijuana twice a week. Medical treatment was received in Hospital Emergency Departments. In previous employment Gordon's primary occupation was a cook. He was often heard proudly referring to having once won a 'Chef of the Year' award and had his photo published in the local newspaper.

Gordon had facial injuries at the time of interview, that appeared to have been as a result of an assault. Initially Gordon stated that he did not recall what had happened but later stated the injuries were the result of tripping over his dog when he was, "a little under the weather". The interview in Gordon's housing unit was disrupted on several occasions by people entering unannounced. One man appeared alarmed to find interviewers present and without any interaction hastily proceeded to walk through to the kitchen, never to reappear (we later came to discover that he had exited via the kitchen window).

Another neighbour arrived part way through the interview and without invitation joined the discussion. This man proceeded to respond on Gordon's behalf in an authoritative manner. He appeared substance affected and attempted to dominate the conversation. It was apparent that this man was well known to Gordon and he spoke of a seemingly genuine concern for Gordon's welfare.

After witnessing these interactions, interviewers suspected that Gordon was indeed being exploited. A suspicion that was later confirmed by Gordon's carer who informed the interviewers that his facial injuries were not sustained through a fall but as the result of an altercation with the man who had interrupted our meeting. The carer also informed interviewers that neighbours were often seen to help themselves to Gordon's food, including his Meals on Wheels. In return they would occasionally share their alcohol and marijuana with him. One endearing comment made by Gordon was that he would always prioritise the purchase of dog food ahead of alcohol and cigarettes and that he always ensured that the dog was walked every day. This was confirmed by his carer.

Neuropsychological reports confirmed the presence of an ARBI and severe memory impairment as a result of the traumatic brain injury. It also reported that Gordon had no discernable degree of insight into his alcohol abuse and did not consider his drinking to be a problem. File notes and reports revealed a history of depression and a previous diagnosis of schizophrenia, although discussion between the neuropsychologist and a treating psychiatrist indicated no current signs of psychosis and Gordon was no longer on anti-psychotic medication. The neuropsychology report indicated that symptoms of psychosis may have been in the context of brain injury recovery. Gordon's alcohol consumption reported to the neuropsychologist was significantly lower than the amount he reported to interviewers, a cask of wine every 2-3 days if consuming alone or more when sharing with friends.

Because of his affinity with the local neighbourhood and uncertainty of the need to separate from his pet, Gordon was initially reluctant to volunteer to move into The Wicking Household. These apprehensions were swiftly allayed through the support of his case manager, carer and Advocate



Guardian. Gordon and his dog had a smooth transition and integration into the Wicking Household. The opportunistic neighbours who feigned genuine concern for Gordon were never heard of again, despite having been provided with the new contact details.

Gordon adapted quickly to his new community and with additional support began to access local community programs such as exercise classes and walking groups. Gordon explored his local area during daily walks with his dog. Despite the procedures initially established to support Gordon in his new community, he would occasionally venture into unfamiliar territory, become disorientated and unable to find his way home. Fortunately the frequency of these incidents reduced as Gordon familiarised himself with the area and staff developed more effective protocols and procedures in response to such incidents.

Gordon eagerly participated in domestic duties, especially cooking. During the first few months of residency, Gordon appeared to enjoy the companionship of his fellow residents although incidents involving explosive verbal outbursts occurred with relative frequency especially when alcohol was consumed in excess of the alcohol program. Neuropsychological support provided staff and Gordon with strategies to assist with reducing the severity and frequency of these volatile incidents which had the effect of intimidating staff and co-residents. However despite this volatility, an unlikely pairing saw Gordon befriending a fellow participant within the Wicking Household – a relationship that he later described as, “The best mate a man could ever have.”

Gordon had participated in the Wicking Household for 12 months at which time an opportunity arose for him to transition to a less supportive residential environment provided within a Wintringham hostel. Gordon welcomed this opportunity on the proviso that his dog could accompany him to his new place of residence. He continues to be supported at this hostel. Gordon also continues his friendship and regularly visits his mate who has since moved into a Wintringham Nursing Home. “I still miss the old bugga,” he says affectionately.

### 2.2.3

#### Overseas ARBI Services Overview

The second element of the first phase of the Wicking Project focussed on investigations aimed at developing a Specialised Model of Residential Care to be adopted for use in The Wicking Project Trial. It was decided to build the specialised model from the foundation of the existing Wintringham model. The findings of the Wintringham service investigation identified aspects of the Wintringham model that have allowed the service to continue to successfully house and support older people with a history of hardship, homelessness, disadvantage and challenging behaviours. This was supplemented by the findings of the literature review undertaken during the Project’s incubation phase, interviews with Australian service providers and the outcome of overseas investigations.

Site visits to overseas services specialising in the provision of residential care to older people living with an ARBI were undertaken to inform The Wicking Project. These visits were completed over a two week period in July 2007. A total of 20 Homeless/AOD services in The Netherlands and UK were visited. A full report on these visits to services in England, Scotland and The Netherlands was completed and can be viewed on the Wintringham website. Some general observations made in this report are discussed below.

Residential services specific to older people with an ARBI were of a higher quality in The Netherlands and Scotland than in England. Both the Scottish and Dutch services received special funding from Government Mental Health Services in recognition that alcohol and other drug addictions were classified as mental health disorders. All of the high level residential care services visited that specialised in the support of older people with alcohol addiction were dry facilities.

Restricted by the limitation of old building design, most services across all three countries had an institutional-like atmosphere with long linoleum clad hallways and basic government/hospital furnishings. English service providers frequently expressed their frustration with the lack of policy provision and recognition of the special care needs of older homeless people (>65 years old) who were heavy long-term drinkers especially those who were unable or unwilling to maintain sobriety.

For the majority, workers in the facilities visited displayed genuine compassion and desire to provide the best care possible to their client populations, however all too often financial constraints and an institutionalised culture resulted in a limited capacity to think innovatively and explore new opportunities directed toward improving the lives of these individuals. All three countries, in particular The Netherlands, were experiencing increased numbers of older clients presenting with long-term addictions to hard drugs such as cocaine and heroin. These individuals generally presented with a completely different set of behavioural disturbances and specialised care needs.

3

## Phase Two – Trialling The Wicking Model of Care: Project Design

### 3.1 Methodology

3.1.1

#### Participant Recruitment

Human ethics approval for the Wicking Project Trial's evaluation was granted by the full panel of the Austin Health Human Ethics Committee (HREC Approved Project No: H2008/03097). The identification of potential participants in the Wicking Project involved key personnel in services such as major public hospitals, crisis and homeless services, The Office of the Public Advocate, The Royal District Nursing Service Homeless Persons Program (RDNS-HPP) and Residential and Community Housing Programs etc. Potential participants were identified by personnel guided by an identification checklist (Appendix B). A written project description was then individually presented and discussed with each potential participant and their permission obtained for a researcher to establish contact.

The researchers then arranged to meet potential participants at their preferred venue (with an accompanying or advocating representative where appropriate). At the interview, the project evaluation was explained and discussed in detail. The potential participant was then given a detailed Participant Information Form which was also read out to them. Before proceeding with any evaluation, the participant's consent was sought for participation in the evaluation. Together they completed a Participant Informed Consent (Appendix B) form which detailed all of the requirements and expectations of participants in the study evaluation. This was also read aloud and discussed in detail with the participant. Due to the potential for varying levels of cognitive impairment within the Wicking Project Participant Group, both written and verbal informed consent was obtained in the accompaniment of the participant's guardian or carer where appropriate. Once consent was obtained, the person's potential for eligibility for participation was determined by way of an interview.

Although Wintringham delivers all services to both men and women (the current percentage of female clients in residential care is 32% and community care is 56%), with this in mind, it was initially decided that only men would be recruited into the Wicking Trial. The decision was also influenced by the belief that the inclusion of a female participant into this type of small, shared residential environment would introduce an element of unacceptable risk of sexually inappropriate behaviours. However, through the implementation of the trial it became apparent that the significance of this risk had been overestimated. This combined with the disproportionately large number of referrals received for women to participate in the project indicates a scarcity of appropriate residential support options for aging women living with alcohol related brain injury and eventually did lead to a female being recruited as a Wicking Project participant.

Participants were allocated to one of two groups: Wicking Model Participants and Community Control Participants. Due to chaotic lifestyle patterns and the diverse and extreme nature of behavioural traits displayed by many individuals referred to the project, the assignment of participants into the two groups was not undertaken by way of random allocation but rather on a priority needs basis. Eligible participants determined to be in the greatest or most urgent need of specialist residential care and support were prioritised for allocation to the Wicking Model Participant Group. There was a degree of urgency to these referrals with service providers being unable to source appropriate alternative care for their clients, many of whom were engaged in high risk lifestyle activities and practices. The selection of Wicking Model Participants was biased toward

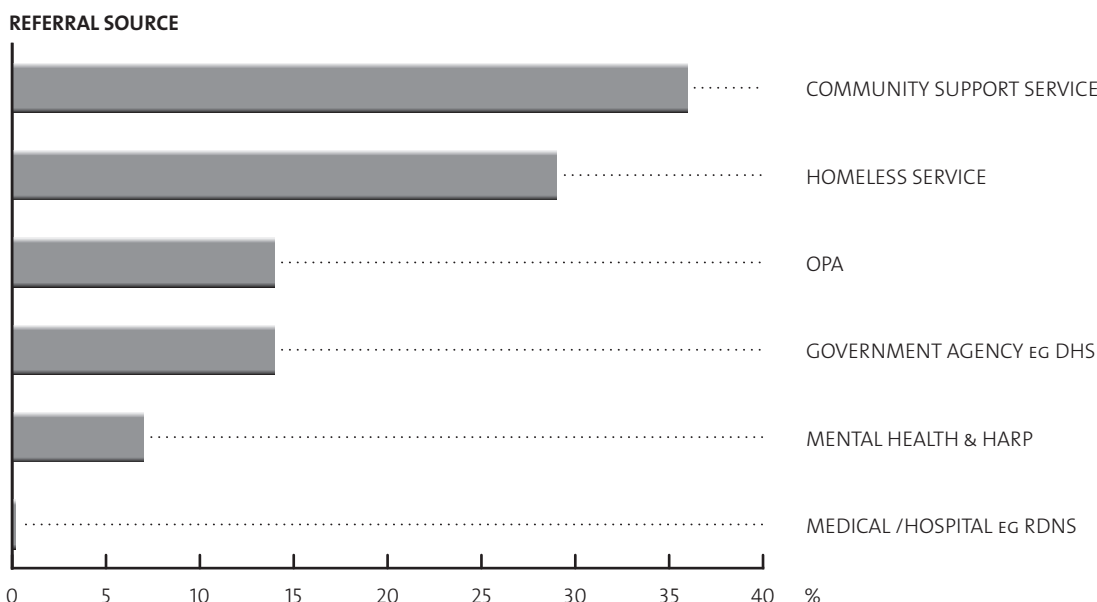
individuals who were amenable to cooperative coexistence with other residents living in a relatively confined shared home environment.

Wicking Community Control Participants were similar to the Wicking Model Participants in their level of Alcohol Related Brain Injury and psychosocial disability. These individuals continued to live their usual lifestyles within the community without project intervention beyond their participation in the trial’s three monthly assessments and outcome measures. All Community Control Participants were monitored while continuing to live in their normal housing environment and engaging with their established service providers (Examples of these lifestyles are depicted in *The Story of Gary* and *The Story of Wayne* later in this report). These participants were prioritised on a waiting list to fill potential vacancies within The Wicking household. In view of the already low statistical power and the explorative nature of this action research, transition of participants in and out of the model was considered to have minimal negative impact on the project outcome measures and could potentially have a positive effect by providing the opportunity to establish more stable inter-resident dynamics.

### 3.2 The Wicking Project Participants

The target population for inclusion in The Wicking Project Trial was older men (aged 50+) with varying levels of cognitive impairment as a result of alcohol-related brain injury ( $n=14$ ). All participants had high behavioural care needs and uncomplicated physical health care needs. Participants were referred from five different sources (Figure 1) of which community support services were the most common.

**Figure 1** Source of Referral for The Wicking Project Participants



| <b>Requisites</b>                                                                                                                                                                                                                                                                                                                                                   |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Is male and aged fifty years or older (later amended to also include females);                                                                                                                                                                                                                                                                                      |
| Is ambulant – i.e. relatively active;                                                                                                                                                                                                                                                                                                                               |
| Has relatively low medical care needs – i.e. with no major health concerns that are unmanaged or ongoing incontinence issues;                                                                                                                                                                                                                                       |
| Has a long-term, continuing excessive drinking problem;                                                                                                                                                                                                                                                                                                             |
| Has an Alcohol Related Brain Injury (diagnosed or suspected). To be confirmed by way of a neuropsychological assessment;                                                                                                                                                                                                                                            |
| Has displayed (confirmed) behaviours of unmet need e.g. challenging, perseveration, aggression etc;                                                                                                                                                                                                                                                                 |
| Has a history of homelessness or risk of homelessness;                                                                                                                                                                                                                                                                                                              |
| Does not have a mental health condition (reported or suspected) such that would prevent them from living collaboratively in a shared home environment;                                                                                                                                                                                                              |
| Does not have an addiction to drugs other than alcohol and cigarettes;                                                                                                                                                                                                                                                                                              |
| Is willing to participate in an eighteen month trial even if there are no guarantees that they will be selected to move into the Wicking Household;                                                                                                                                                                                                                 |
| Is willing to participate and cooperate in major Project Trial assessments (totaling approximately 3 hours) at three monthly intervals during the 18 month trial period;                                                                                                                                                                                            |
| If selected as a Wicking Model Participant, is willing to participate in the trial even though there are no guarantees that residency in the Trial Household will extend beyond the trial completion date (Note: All Wicking Model Participants will be fully supported in making the transition to alternative appropriate accommodation at the end of the trial); |
| Is aware that their participation will not attract any special payments or monetary rewards.                                                                                                                                                                                                                                                                        |
| <b>Preferable</b>                                                                                                                                                                                                                                                                                                                                                   |
| Has a history of unsuccessful or problematic tenancies resulting from behaviours associated with alcohol intoxication;                                                                                                                                                                                                                                              |
| Is eligible for residential aged care;                                                                                                                                                                                                                                                                                                                              |
| 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.                                                                                                                                                                                                                                                                                   |

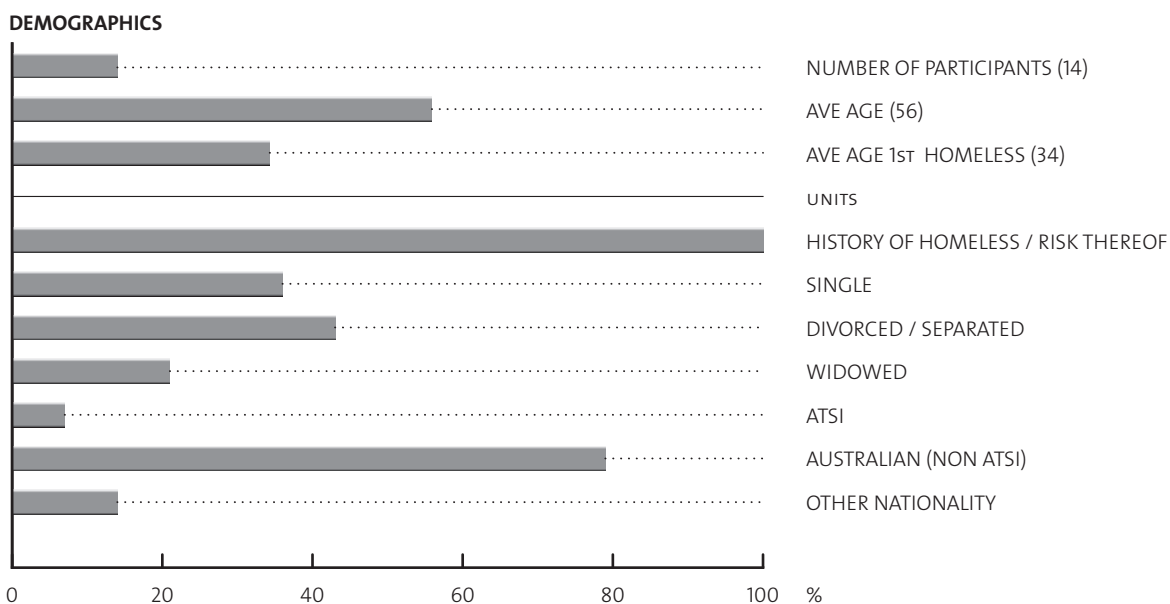
**Table 3** Inclusion Criteria for Wicking Project Participants**3.2.1****Pre-participatory Demographics**

All participants underwent a comprehensive pre-participatory interview from which the following demographic data was obtained. The average age of participants was 56 years (range  $\pm 8$  years) and all had experienced periods of homelessness most of which extended across several years throughout their lives. All participants were single and the majority were divorced or separated. Half of the participants lived alone, mostly in public housing. Referrals were made by residential care facilities that were struggling to provide adequate and continuing support to residents exhibiting



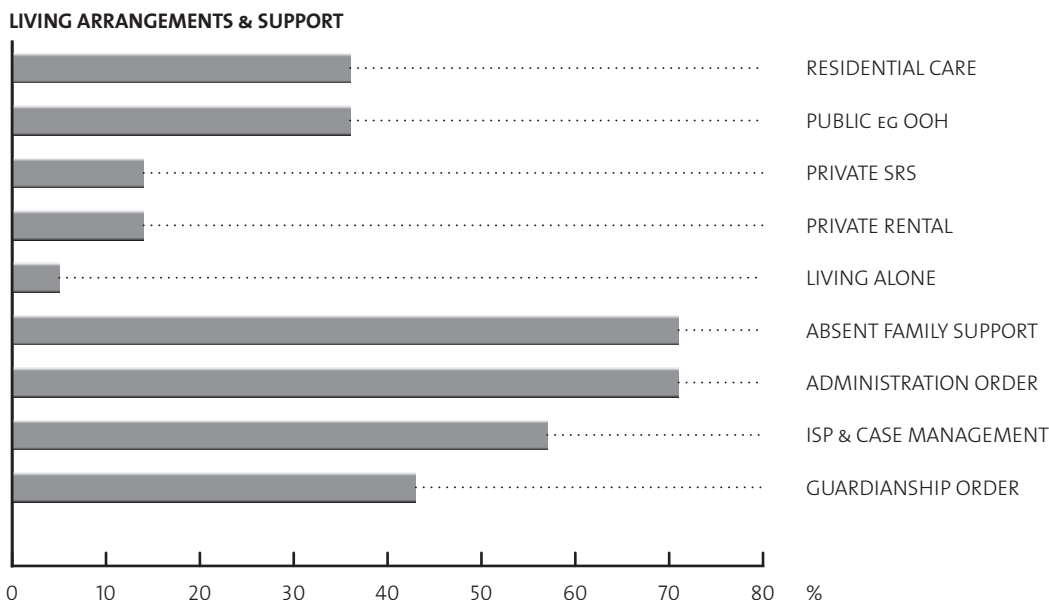
extremely complex and challenging behaviours. The majority of participants had no regular contact with their families and were under administration orders administered by State Trustees. Just under half were under Guardianship Orders with a state-appointed Advocate Guardian through The Office of the Public Advocate (Figure 2 & Figure 3).

**Figure 2** Demographic Data for The Wicking Project Participants (n=14) Prior to the Commencement of The Wicking Trial



32

**Figure 3** Pre-participatory Living Arrangements and Support Networks for The Wicking Project Participants



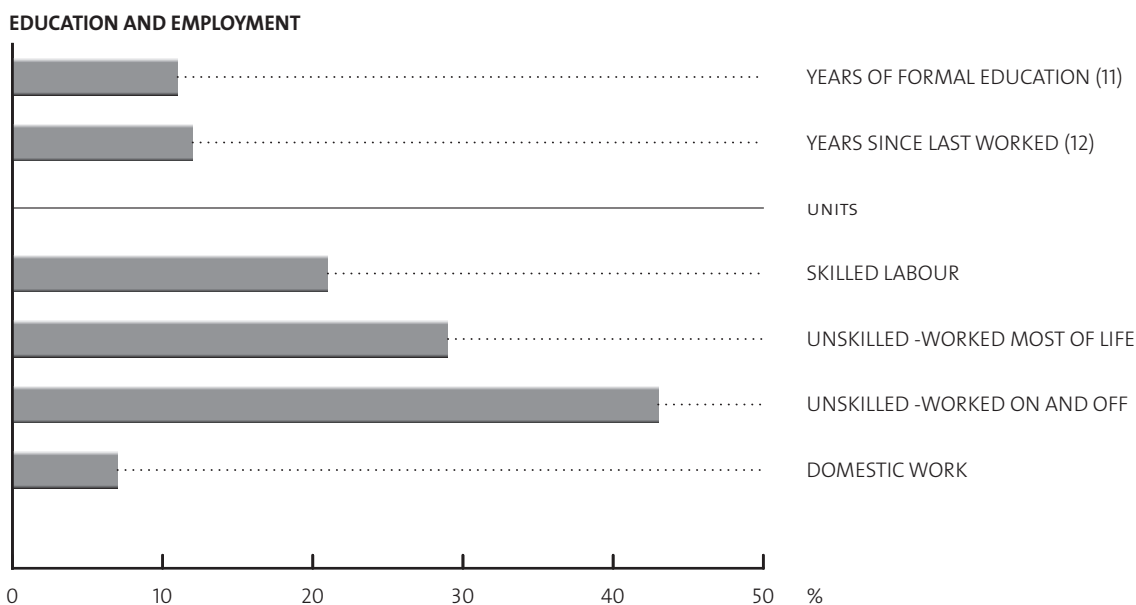
The average level of formal education for participants was between Year 9 and Year 10 with most having been employed in unskilled labour. Most had prematurely ceased work around their mid-forties. The majority of participants reported regular interactions with the police mostly as a result of drinking in public or creating public nuisance. Just under half had previously spent time in prison (Figure 4).

It was remarked in a recent report on difficulties that homeless people face in the court process that:

*'... at least 75 percent of participants received fines and charges in relation to behaviour that was the direct consequence of their homelessness or mentally ill status, including: fines in relation to begging, drinking in public and other public space offences; activities caused by extreme poverty, such as travelling on public transport without a valid ticket or shoplifting food or other necessities; and activities relating to one of the underlying causes of homelessness, such as drug or alcohol dependency. This is consistent with studies in the US and Canada which have found a strong relationship between homelessness, mental illness and low-level crime<sup>62</sup>.*

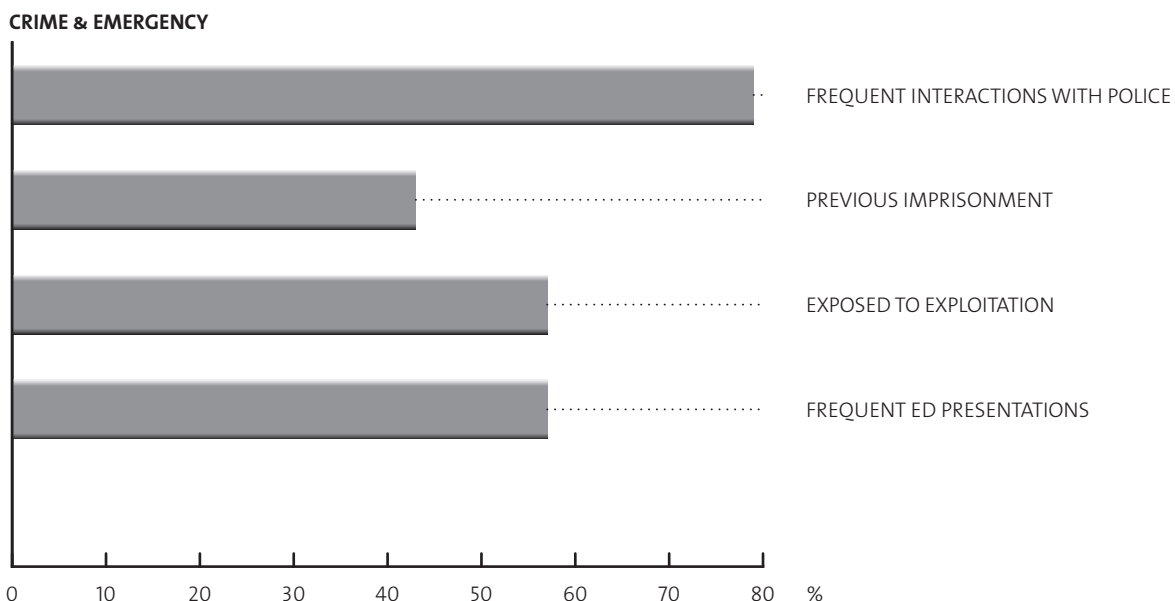
Nearly all participants had been victims of serious assaults (averaging 5.2 physical assaults each year) and most had regularly been the victim of crime (theft of property & abuse). The majority of these crimes were not reported to the police (Figure 5).

**Figure 4** Pre-participatory Education and Employment History of The Wicking Project Participants



At the commencement of The Wicking Project Trial, all participants underwent a comprehensive neuropsychological assessment to confirm the presence of an ARBI. The outcome of these assessments and subsequent investigations confirmed that all participants demonstrated significant levels of ARBI and also revealed a pre-morbid intellectual range from average intelligence to borderline impairment. At the time of initial testing this range had dropped from borderline 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) and learning and memory (Figure 6). This pattern of cognitive impairment is characteristic of ARBI<sup>44</sup>.

**Figure 5** Pre-participatory Crime and Emergency Service Interactions by The Wicking Project Participants

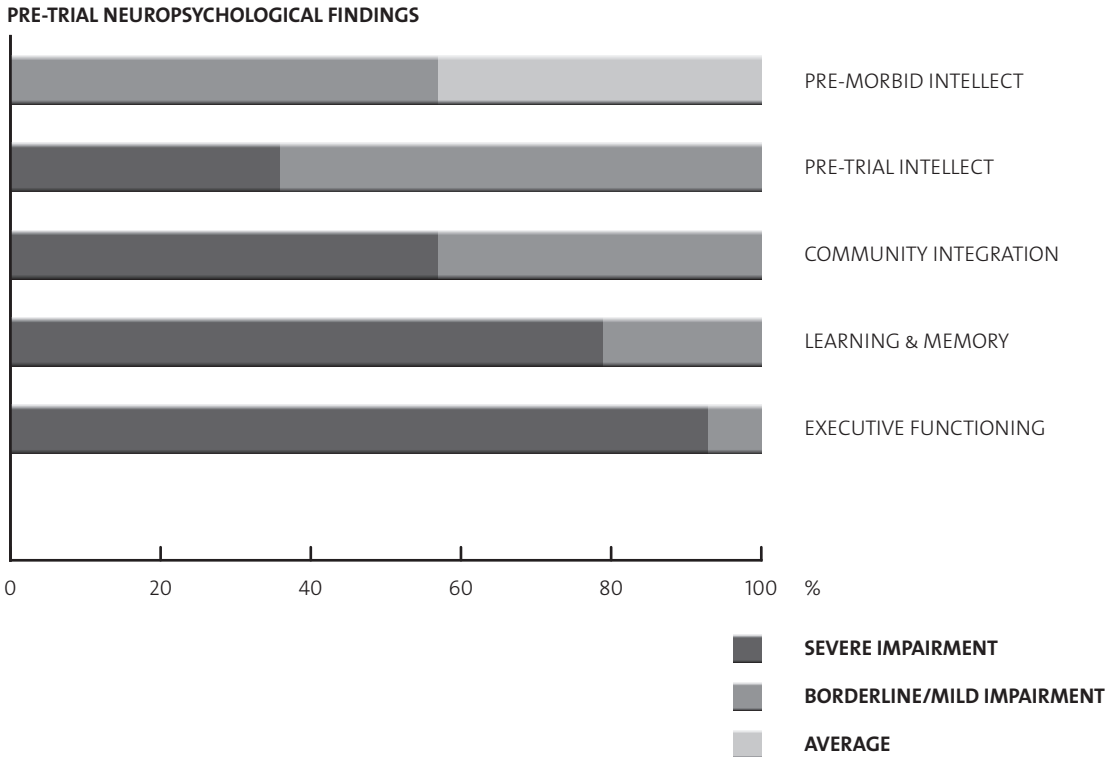


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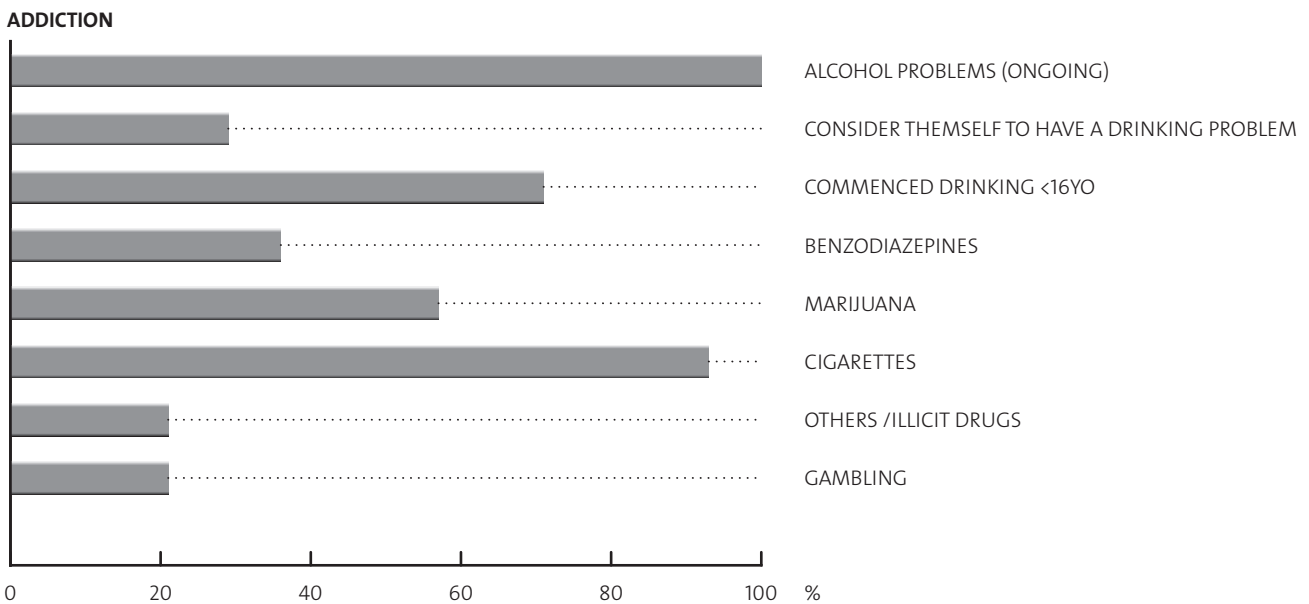
All participants were active heavy drinkers and the majority had experienced multiple failed attempts at sobriety through a number of different support services (Alcoholics Anonymous, rehabilitation and detoxification units). Between two participants a total of 58 admissions to detoxification units had been reported over a span of 10 years. Seventy-one percent of participants commenced drinking prior to 16 years of age. The drinking pattern of most participants was relatively constant with sporadic binges that fluctuated with access to finances. At times when finances were flush, the upper limit of reported drinking levels included two 3-litre casks of wine per day or a slab of heavy beer plus a bottle of spirits each day. Only one third of participants acknowledged that they had a drinking problem (Figure 7). This misconception could be attributed to the presence of frontal lobe brain injuries associated with ARBI which commonly manifest in poor levels of insight and could also be attributed to continued patterns of heavy drinking due to impaired impulse control and decision making ability.

All but one participant smoked heavily placing them at significant financial strain. For nearly all participants, the purchase of alcohol and/or cigarettes very frequently took precedence over the purchase of food although one participant who owned a pet did place priority on the purchase of pet food. Marijuana was the most commonly used illicit drug but for the majority it was only used occasionally. Benzodiazepines were the next frequently abused other drug with two participants actively seeking the drug through frequent presentations at hospital emergency departments with feigned symptoms.

**Figure 6** Neuropsychological and Community Integration Findings for Wicking Project Participants Prior to Wicking Trial Participation.



**Figure 7** Reported Addictive Behaviour Exhibited by Wicking Project Participants Prior to The Wicking Trial



The nature of challenging behaviour exhibited by 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 8). These behaviours in various forms were reported for

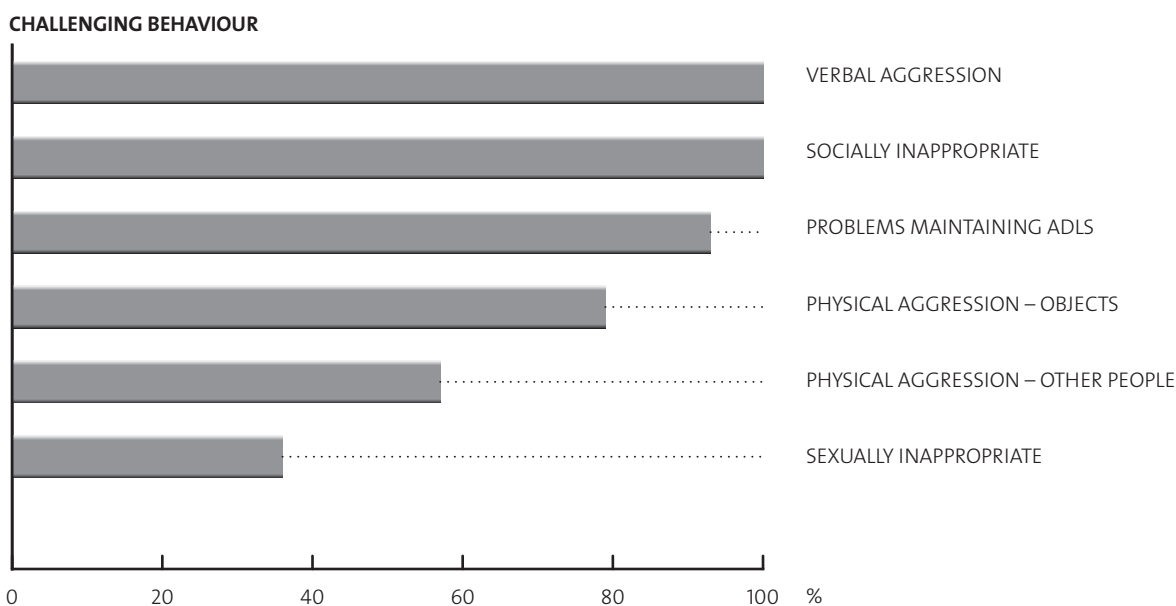
all project participants. Examples of verbal aggression included the frequent use of profanities, loud abusive language and the making of threats of harm to neighbours, police, care staff and hospital staff. Examples of socially inappropriate behaviour included being socially awkward, creating a nuisance or annoyance, non compliant or oppositional behaviour, engagement in petty crime or unlawful behaviour and by far the most common was presenting a danger or risk to self or to others.

Physical aggression directed toward objects included lighting fires in domestic environments and the breaking or throwing of furniture and fittings. Physical aggression directed toward other people included spitting, hitting people with walking sticks, and pushing or lashing out toward people. Examples of sexually inappropriate behaviour most commonly involved sexually inappropriate comments or insinuations but also included inappropriate touching or groping.

Most commonly reported problems with self-maintaining and instrumental Activities of Daily Living (ADLs) included failing to maintain personal hygiene, nutritionally balanced dietary intake, medication compliance and a safe and hygienic living environment.

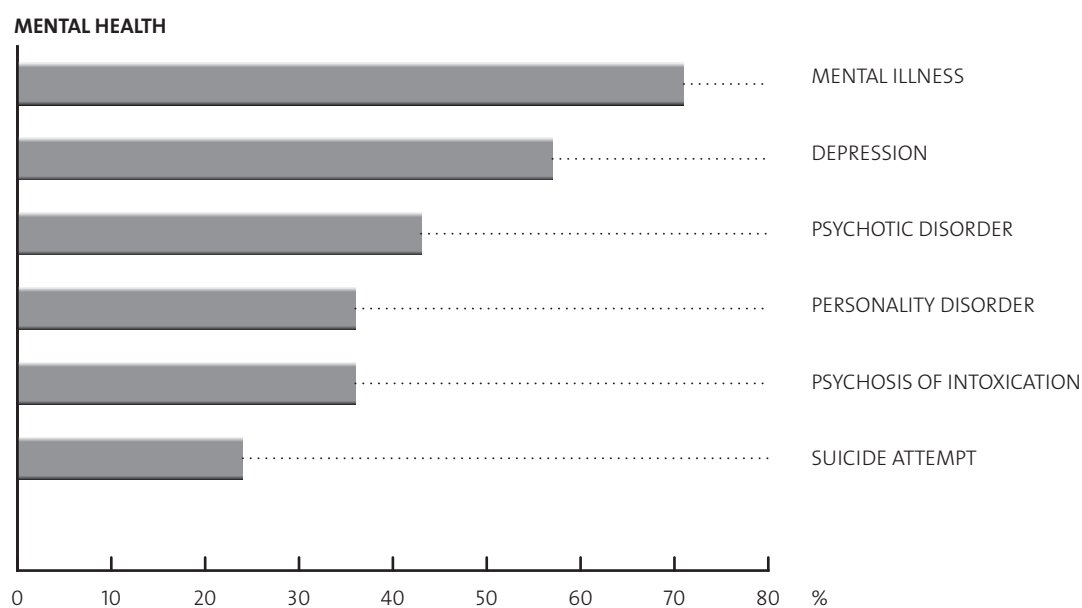
36

**Figure 8** Reported Incidence of Challenging Behaviour Exhibited by Wicking Project Participants Prior The Wicking Trial



There was a high prevalence (71%) of mental health problems within our participant population of which depression and psychotic disorders were the most common (Figure 9). A little over one third of participants had diagnosed personality disorders of which an antisocial disorder was the most common; however, several more participants demonstrated complex personality traits. A quarter of the participants had previously attempted suicide. Thirty-six percent of the participants were diagnosed with a condition referred to as ‘psychosis of intoxication’ or ‘alcohol-induced psychotic disorder’ (AIPD)<sup>63</sup>, which is a rare complication of excessive alcohol use. The disproportionately large representation of this condition within the Wicking Project Participant Group indicates possible overuse of this diagnosis or, in a few instances, a failure to identify symptoms that occur secondary to simultaneous ‘other’ drug use. This unfortunately has significant negative consequences for the person labelled as such because it creates almost impenetrable barriers to accessing appropriate mental health support services.

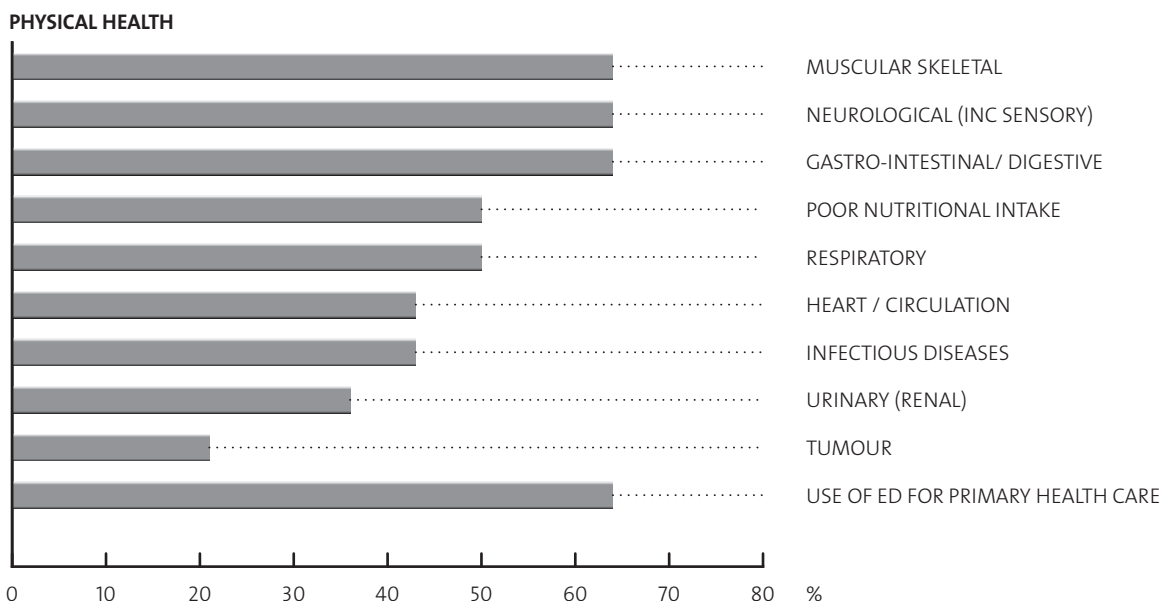


**Figure 9** Reported Mental Health Problems Among Wicking Project Participants Prior to The Wicking Trial

Not surprisingly the health status among Wicking Project Participants was reflective of a population of significantly older age (Figure 10). 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). For example, one participant sustained broken ribs and a jaw injury from a recent fight, another had multiple pins and plates inserted in his leg to repair injuries sustained in a motorbike accident. The most frequent neurological disorders aside from the ARBI were traumatic brain injuries 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 alcoholic beverages over an extended period of time<sup>64</sup>. Hepatitis was the most common infectious disease present within the participant population. For the majority, primary health care was principally accessed via the public hospital emergency department.

Gastrointestinal problems and poor nutritional intake were the next most common disorders. 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. Other 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<sup>65</sup>. The high prevalence of renal disorders can also be attributed to 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<sup>66</sup>.

**Figure 10** Reported Incidence of Physical Health Problems Among Wicking Project Participants Prior to The Wicking Trial



### 3.3 The Wicking Trial Communication Strategy

Given the focus of the Project was on systemic change, active dissemination was a major factor in the project activity. All Wicking Project reports were circulated to key external stakeholders, service providers and Government bodies. Strategies for report dissemination included:

- a Developing and running forums;
- b Arranging meetings with state and federal politicians and policy makers;
- c Publishing articles and manuscripts in such local and international publications;
- d Attendance and delivery of papers or workshops to such forums as conferences and conventions;
- e Involvement of Advisory Committee Members in industry and Governmental forums, focus groups and panels;
- f Development of an ongoing rapport and information exchange with state and federal politicians and policy makers.

### 3.4 Governance of The Wicking Project

The Wicking Project was governed by the Project Management Committee which received guidance and advice from The Wicking Project Advisory Committee (Figure 11). 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.

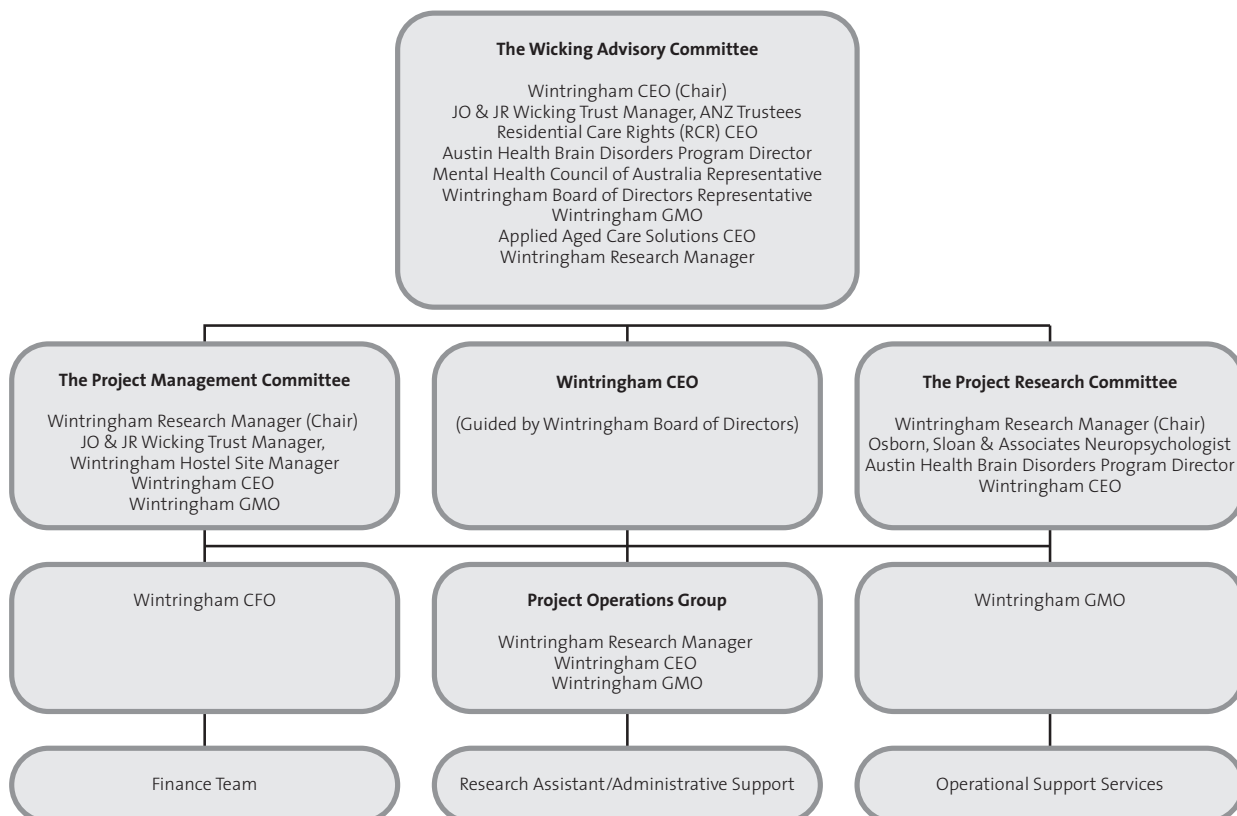
The Wicking Project Operations Group met daily to weekly and oversaw the day to day operations of the project. The Operations Group was a subgroup of the Wicking Project Management Committee which met on a monthly basis. The Management Committee provided regular progress updates to The Advisory Committee which met on a quarterly basis (or more frequently as required) to provide continuing input and advice on issues relating to Project strategy and development.

The Research sub-committee comprised members of the Project’s Management & 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 in compliance with current research practice;
- were not introspective;
- were regarded as credible and valid;
- achieved academic/sector/government recognition and acceptance.

Ongoing liaisons with The Commonwealth Department of Health and Aging, particularly focussed around enquiries into homelessness, complex behaviours, mental health and aged care funding reforms have enabled The Wicking Trial to be cited as an example of a project designed to address these issues using a valid and scientifically robust approach. Interest in the development and progress of the Wicking Project has been increased in this arena. This is a positive step toward achieving the aim of influencing change in government policy and funding structure in support of long term care solutions for this disadvantaged and marginalised group of people.

**Figure 11** The Wicking Project Organisational Chart



### 3.5 The Wicking Project Model of Care – Overview

Seven participants participated in the Wicking Model of Care (Wicking Model Participants). They resided in a specially modified dedicated 4-bedroom home neighbouring an existing Wintringham low-level residential aged care facility in Flemington, 4.5 kilometres from Melbourne’s CBD. The

Wicking Model Participant Group received 24 hour (1.5 Effective Full Time) carer support that addressed individual social, psychological and physical needs. All participants had a history of severely affected behaviours associated with significant levels of ARBI and were selectively recruited for a history of homelessness or high risk of homelessness arising from these behaviours. All Wicking Model Participants received individualised specialised care support and individualised controlled drinking and smoking programs (Appendix C). These initiatives included individualised behaviour management support, specialised case management and a one-on-one structured activity program, all of which were maintained by a team of highly trained and skilled personnel including ongoing specialist neuropsychological case management.

A detailed discussion of the Wicking Model of care will feature later in this report; however the following will provide an overview of key characteristics of the model:

40

- Based on the current Wintringham model of residential care with specialisation in the area of supporting older people living with complex needs arising from an ARBI;
- Emphasis on routine and consistency yet allowing for variances and modifications according to a structured process;
- Individualised alcohol and cigarette management programs;
- Financial management if required;
- Intensive individualised recreation/structured activity program focussing on off-site community-based activities;
- Medical support to be provided by a dedicated GP;
- Utilise current Wintringham care plan and behaviour management documentation/policies and practices which comply with Aged Care and Accreditation standards.

## 4 Phase Three – Project Evaluation

### 4.1 Methodology

The aim of the Wicking Project's evaluation was to provide evidence that will make a significant contribution to improving the life quality of older homeless people living with severe behavioural disturbances and to identify gaps that exist within the current service system. This action research was exploratory in nature and therefore incorporated both qualitative and quantitative outcome measures. The mixture of quantitative and qualitative methodology enabled the capturing of information about the process and outcomes of the project in such a way as to maximise the benefit to individual participants. This methodology also facilitated the evaluation in producing outcome data that could be transferred and disseminated to national and international audiences.

As to the challenges of psychosocial research involving multiple interventions, the apparent discrepancies between controlled and clinical research are pertinent since efficacious studies in residential settings are unlikely to occur. Identified methodological weaknesses in this project include; small non-randomised sample size, variability and unreliability of participants, non-standardised interventions, minimal sources of information and the constant influence of alcohol intoxication on assessment scores. In such circumstances, research needs to better reflect the systemic complexities of the intervention process. Although some researchers continue to advocate that the standard for research practice needs to be traditional experimental or quasi-experimental designs, qualitative, inductive approaches are better suited to the complexities and dynamics of such psychosocial interventions. This approach is sometimes referred to as 'effectiveness research'<sup>67</sup>. Although there are methodological difficulties in effectiveness research, especially in such a complex setting as The Wicking Project, it does capture the complexities of the intervention process.

Qualitative descriptions of life history and life issues faced by Wicking Project Participants were completed e.g. observations, interviews with participants, their carers, family etc. Investigations to ascertain clinical history (mental & medical) including health services utilisation, criminal justice system interactions and crisis/housing services utilisation were also completed. Quantitative measures including neuropsychological assessments, depression and aggression scales, life satisfaction and quality of life assessment tools were undertaken to determine the effect of interventions.

Staff input was obtained to evaluate not only individual participant outcomes but also non-direct care processes involved in the evolution of the model. This information was collected by way of regular staff forums (such as team meetings or behaviour management reviews and through participation in evaluative processes and focus groups).

The same evaluative methodology was undertaken for all 14 participants thereby creating control data. This enabled us to complete economic modelling comparing the cost of intervention to non-intervention life pathway scenarios e.g. crisis accommodation, imprisonment, secure locked facilities, emergency hospital and psychiatric care etc.

More specifically, the evaluation aimed to assess the impact of this novel intervention on cognitive performance, neuropsychiatric disorder, social functioning, ADL (Activities of Daily Living) functioning and particularly life role participation. Life role participation as measured by the Life Role Questionnaire<sup>86</sup> was considered the primary outcome measure for this study. It is a self-rated measure of participation or identification with various occupational and social life roles.

In view of the small number of participants, the power of intervention was increased through the systematic collection of evidence including pre-, inter- (3 monthly) and post-trial measures for all 14



participants. Information gained from these assessments was not doubly blinded and were utilised in an iterative manner in the delivery of appropriate care to the participants.

#### 4.1.1

### Evaluation Inventory

**Wechsler Adult Intelligence Scale – 3rd Edition (WAIS-III)**<sup>68</sup>. The WAIS-III 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>69,70</sup>. Domains of cognitive function assessment by the WAIS-III include information processing, abstract verbal reasoning, arithmetic ability and visuo-constructional ability. Scores derived from the WAIS-III that were used in the study include individual subtest scores from the following subtest: 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 also are used.

**Wechsler Memory Scale – 3rd Edition (WMS-III)**<sup>71</sup>. The WMS-III 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 (HVL)**<sup>72</sup>. The task 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 HVL 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>73</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>74</sup>.

**Controlled Oral Word Association Test (COWAT)**<sup>75</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>76</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>77</sup>. This task has two conditions. The first condition 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 coloured “1”, to a yellow coloured “2”). The test is used as a measure of executive function.

**Wechsler test of adult reading (WTAR)**<sup>78</sup>. 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.

**The Hospital Anxiety and Depression Scale (HADS)**<sup>79</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>80</sup>. It is relatively unaffected by concurrent physical illness<sup>81</sup>.

**Satisfaction with Life Scale (SWLS)**<sup>82</sup>. The scale 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>83</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>84, 85</sup>.

**Life Role Checklist<sup>86</sup>.** The 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>87</sup>. It has also been used successfully in research with older people<sup>88</sup>. In this study, individuals were asked to rate their current involvement in each life role.

**The Neuropsychiatric Inventory Questionnaire (NPI-Q)<sup>89</sup>.** The NPI-Q is a rapidly administered instrument that provides a reliable assessment of behaviours. It assesses 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 provide 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 provides a useful tool in the assessment of the severity of the symptoms and the distress the symptoms cause to the caregiver.

**The Alcohol Use Disorders Identification Test (AUDIT)<sup>90</sup>.** The AUDIT was developed by the World Health Organisation to identify persons whose alcohol consumption has become hazardous or harmful to their health. The AUDIT is a 10-item screening questionnaire with 3 questions on the amount and frequency of drinking, 3 questions on alcohol dependence, and 4 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.

**The Overt Behaviour Scale (OBS)<sup>91</sup>.** The OBS is designed to clarify the types of observable challenging behaviours that can occur following acquired brain injury (ABI). This can help to show how behaviours may have changed over time and can inform decisions related to clinical interventions. This 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). There are 9 categories of behaviour that can be scored on this scale; they 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, Lack of initiation. This scale scores the severity, frequency, and impact of each behaviour.

**The Health of the Nation Outcome Scales (HoNOS)-ABI<sup>92</sup>.** The HoNOS-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. In making their ratings, the clinician makes use of a glossary which 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 Acquired Brain Injury. 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 was used to measure community integration. It provides accurate measurement of key concepts that define community integration which are integral to acquired brain injury rehabilitation<sup>93</sup>. The CIQ is the most widely used and researched measure of community inclusion in rehabilitation literature<sup>94, 95, 96, 97, 98</sup>. The CIQ 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.

After deciding on the most appropriate outcome measures to be implemented in The Wicking Project Trial, Wicking Model Participants were successfully recruited to move into the Wicking residence. An intensive transition period followed, during which time the participants moved and settled into their new home and individual care plans and behavioural profiles were established.

#### 4.1.2

### Statistical Analyses

That which may be considered small achievements or advancements among individuals within a normal aged population can indicate significant milestones along the path of improved life quality for individuals who have lived a life of impoverishment and disadvantage. Therefore the analysis employed in The Wicking Project Trial was primarily descriptive, although simple statistical tests were used to enable comparisons to be drawn between the two groups bearing in mind that these comparisons were based on a small number of participants ( $n=14$ ). Statistical Package for the Social Sciences (SPSS) Analytical Software was used to analyse these data. Statistical significance was set according to the convention level of  $P < 0.05$ .

## 5 Wicking Project Outcomes

### 5.1 Outcome Summary

The Wicking Model has the potential to be packaged as a transitional care model from which participants emerge with the potential to successfully transition from a highly intensive care environment into the mainstream funded care of specialist service providers such as Wintringham. Some other major learnings have emerged from The Wicking Project Trial which educe optimism as to the potential of The Wicking Model in bringing about effective change in Government policy and more importantly, in participant wellbeing and life quality. This outcome was well beyond initial expectations – for a model which was originally designed to provide a long-term residential care solution to a few, to a model that could potentially result in breaking the cycle of chronic homelessness for many. Another striking outcome of this project are the calculated savings to Government achieved through The Wicking Model as opposed to life on the streets.

The dominant economic techniques used for the review of Government programs and policies are: cost benefit analysis; cost-effectiveness analysis; and cost-utility analysis. Very few comprehensive cost-benefit studies have been conducted in Victoria, however, a study from Western Australia<sup>106</sup> shows that Governments can save money by providing secure housing and support to homeless people because of the large corresponding reductions in health, forensic and crisis support costs. The nature of The Wicking Model intervention and the complexity of the problems it addressed meant that it was not possible to utilise any of these standard techniques to undertake a formal cost-benefit, cost-effectiveness or cost-utility analysis in evaluating this program. We therefore employed the technique of comparing the frequency of service usage for participants of The Wicking Model to those of the Community Control Group and in doing so, calculated a saving of approximately \$30 per person per day (Table 4). Table 4 represents the accumulative cost of service usage for four participants within each group. The rationale behind the selection of four participants to include in this costing was influenced by an undertaking to match participant groups with regard to comparable intervention timeframes and number of successfully completed data sets.

These savings come despite the fact that balance of costs did not favour The Wicking model for the following reasons:

- They include costly residential service establishment and initiation costs;
- All Wicking Model Participants were admitted at approximately the same time thereby placing significant resource strain on supporting participants through transition and managing the simultaneous peaks in behavioural challenges experienced around the three-month stage of residency (discussed in more detail later);
- The recruitment strategy was biased toward the recruitment of participants demonstrating the greatest level of need or those experiencing urgent life crises. As a result, Wicking Model Participants represented a population experiencing a higher frequency of challenging behaviour compared to the Community Control Population. This is evidenced by the project measurement outcomes discussed later in Chapter 5.4.1 .
- Nearly all incidents of emergency service engagement for participants in The Wicking Model were accurately recorded whereas the recording of these incidents among the Community Control Participants was based on subjective reporting. This had the potential to represent a significant element of under-reporting due to the following factors:
  - Presence of significant memory impairment and poor recall;
  - The fear of being judged negatively for their involvement particularly with police;
  - Assumptions that these interactions are ‘normal’ every day experiences.

| Community and Aged Care Services                     | Wicking Model Participant Episode Frequency+ | Community Control Participant Episode Frequency~ | Cost (\$) per Day/ Occasion#^ | Wicking Model Participant Accumulative Cost (\$) | Community Control Participant Accumulative Cost (\$) |
|------------------------------------------------------|----------------------------------------------|--------------------------------------------------|-------------------------------|--------------------------------------------------|------------------------------------------------------|
| Crisis accommodation                                 | –                                            | 7                                                | 138.00 <sup>99</sup>          | –                                                | 966.00                                               |
| Specialised Residential Aged Care                    | 1,106                                        | –                                                | 186.68 <sup>100</sup>         | 206,468.08                                       | –                                                    |
| Public Housing                                       |                                              | 158                                              | 16.50 <sup>101</sup>          | –                                                | 2,607.00                                             |
| Supported Residential Service                        | –                                            | 1,056                                            | 8.40 <sup>102</sup>           | –                                                | 8,870.40                                             |
| Rent Assistance                                      | –                                            | 1,489                                            | 7.93                          | –                                                | 11,807.77                                            |
| Case Management – Community Aged Care Package (CACP) | –                                            | 1,067                                            | 36.07 <sup>103</sup>          | –                                                | 38,486.69                                            |
| Multiple & Complex Needs Initiative (MACNI)          | –                                            | 552                                              | 512.34 <sup>108</sup>         | –                                                | 282,811.68                                           |
| Regional Mental Health Case Management               | –                                            | 552                                              | 8.59 <sup>104</sup>           | –                                                | 47,41.68                                             |
| Home & Community Care Services (HACC)                | –                                            | 990                                              | 5.14                          | –                                                | 5,088.60                                             |
| Police attendance                                    | 6                                            | 33                                               | 164.17 <sup>105</sup>         | 985.02                                           | 5,417.61                                             |
| Police overnight lockup                              | –                                            | 2                                                | 145.69 <sup>105</sup>         | –                                                | 291.38                                               |
| Ambulance Attendance                                 | 1                                            | 65                                               | 637.16 <sup>106</sup>         | 637.16                                           | 41,415.40                                            |
| Public Hospital Emergency                            | 9                                            | 61                                               | 406.39 <sup>106</sup>         | 3,657.51                                         | 24,789.79                                            |
| Public Hospital bed – General ward                   | 5                                            | 36                                               | 649.66 <sup>107</sup>         | 3,248.30                                         | 23,387.76                                            |
| Public Hospital bed – Psychiatric ward               | –                                            | 40                                               | 860.62 <sup>108</sup>         | –                                                | 34,424.80                                            |
| GP visits                                            | 30                                           | 20                                               | 41.65 <sup>106</sup>          | 1,249.50                                         | 833.00                                               |
| Alcohol Detoxification Unit                          | –                                            | 10                                               | 1,082.40 <sup>108</sup>       | –                                                | 10,824.00                                            |
| <b>Total Expenditure (\$)</b>                        |                                              |                                                  |                               | <b>216,245.57</b>                                | <b>496,763.56</b>                                    |
| <b>Cost per Person per Day</b>                       |                                              |                                                  |                               | <b>\$195.52</b>                                  | <b>\$224.98</b>                                      |

**Table 4** Cost to Government Comparisons for Service Delivery to Wicking Model Participants Compared with Community Control Participants\*

Notes: \* Frequency data based on four Wicking Model Participants and four Community Control Participants over an accumulative timeframe. + Based on 1106 accumulative days. ~ Based on 2208 accumulative days. # This table shows the estimated amounts provided by the Commonwealth Government, 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 1.47%, 2000 4.48%, 2001 4.38%, 2002 3.0%, 2003 2.77%, 2004 2.34%, 2005 2.67%, 2006 3.54%, 2007 2.33%, 2008 4.35%, 2009 1.82%.



## The Story of Trevor (Aged 64 years)

Trevor was referred to The Wicking Project by the manager of a Residential Aged Care facility where he had resided for five months. The manager reported concerns of challenging behaviour including regular participation in group alcohol binge drinking sessions, frequent incidents of verbal aggression and physical threats toward staff and co-residents. Poor personal care and incontinence when intoxicated were also issues of concern.

At an initial interview to determine eligibility for the Wicking Trial, Trevor presented as a proud, stern character with an extremely guarded demeanour. Trevor glared at interviewers throughout the session with a threatening and hostile gaze. His physical stance and eye contact was intimidating. He was difficult to engage in conversation and reluctant to answer questions giving only brief responses. Offering little information and showing signs of agitation, the interviewers were wary and reluctant at times to press on with questioning but cautiously persevered.

Trevor stated that he retired three years ago after 25 years 'on the tools' as a builder/carpenter – a job in which he supervised up to 25 staff. Trevor reported infrequent contact with his daughter, although this was not corroborated. Trevor appeared to have difficulty recalling details about his past and both interviewers and neuropsychologist suspected confabulation. A neuropsychological assessment revealed conflicting levels of self reported alcohol consumption varying from six cans of heavy beer per day to two slabs per day.

Trevor reported becoming homeless approximately two years ago as a result of a relationship breakdown. He spoke of being unhappy in previous accommodation including a hostel and SRS (Supported Residential Service), stating that he did not like the other residents as they were too young. Trevor spoke of increased alcohol consumption after the death of his wife, approximately 8 years prior. He had been critically stabbed in the abdomen by a previous partner some six years earlier. He claimed not to have consumed alcohol for the past two weeks.

Trevor moved into the Wicking Household in May 2008. Successful implementation of behaviour management strategies and Trevor's new environment enabled staff to positively engage with him. He enjoyed companionship and conversing with others. The transformation in Trevor's interactions was remarkable as he assumed the role of patriarch within the household. He took great pride in his new home and keenly participated in domestic chores, frequently reminding others of their responsibility to do so also.

Trevor formed good relationships with co-residents and staff. With the support of the recreation program, he purchased entertainment equipment including a TV, stereo and a computer. Although initially reluctant to engage in recreational activities, Trevor came to look forward to planned outings.

Incidents of challenging behaviour became less frequent with the majority of behaviours occurring at times when Trevor had consumed additional alcohol (beyond his alcohol program) and at other times when he sensed a loss of control over his environment and life. Comprehensive health assessments determined that long-term alcohol consumption and self neglect had taken its toll on Trevor leaving him with severe peripheral neuropathy, skin lesions, poor dental health and osteoporosis.

Researchers maintained regular contact with the referring agency who were surprised and pleased to hear of Trevor's remarkable progress in the Wicking Household.

Unfortunately in May 2009 Trevor sustained a hip fracture as a result of a fall. He was admitted to hospital and underwent surgery resulting in significant post-operative delirium with an increase in residual cognitive impairment (relative to pre-surgical impairment). Unfortunately, on discharge from hospital, Trevor was unable to return to the Wicking Household and was admitted to a Wintringham Nursing Home due to the increase in his care needs.

Trevor was sorely missed by a co-participant and friend in the Wicking Household who affectionately referred to him as the 'old sod'. Trevor's friend continues to visit 'his life long mate' in the Nursing Home.

Trevor's success in a highly supportive model of residential care had prepared him well for a successful step-down transition to mainstream specialist care. All involved in supporting Trevor were saddened that this did not eventuate for him.

## 5.2 Major Learning Outcomes – Operational

### 5.2.1

#### Transitional Model

During The Wicking Trial implementation the project scope underwent considerable change as a result of unexpected positive outcomes achieved by the majority of Wicking Model Participants. After having received a minimum of 5 months intensive specialised support, participants successfully transitioned out of The Wicking Model into Wintringham residential care. The success of this ‘step down’ integration has led to a greater understanding of what is achievable through The Wicking Model. The model effectively transformed from an intensive support model that could provide a small number of individuals with long-term residential care to a more innovative transitional model that could potentially support many individuals for as long as needed to make a successful transition to mainstream specialist care.

48

No such specialty service currently exists within the Australian service system. This leaves very few options to service providers who are faced with the challenge of sourcing appropriate accommodation and care for older clients living with an ARBI and challenging behaviour. During the Wicking Project Trial, numerous community service providers such as The Office of the Public Advocate and Disability Support Services expressed their relief on hearing of the opportunity to finally being able to refer clients to a residential care environment in which they felt confident that the special needs of their clients would be appropriately supported.

### 5.2.2

#### Targeted Structured Activity Program

Older men and women from homeless backgrounds often have not had the opportunity to access or develop life-long recreational pursuits such as sporting activities, hobbies or community group memberships. Factors such as financial and health constraints have often prevented these people from pursuing recreational interests. It is apparent that lack of social interaction and support networks, be it family or friends, and financial constraints are major barriers for homeless individuals. The absence of regular physical and social outlets can leave individuals vulnerable to further isolation, loneliness and inactivity<sup>109</sup>.

The Wicking Structured Activity Program was seen as a linchpin to providing participants with a full and rewarding lifestyle. The program was characterised by a process that assisted participants to pursue any desired recreational interest or life choice. Recreation staff spent dedicated time with each participant identifying these interests, and then determining the barriers restricting them from participating. This was often a slow process of building rapport and gaining trust. The final stage in this process was the removal of restrictive barriers through innovative approaches with minimal impact on the enjoyment rewards.

For most participants, brain injury had affected their ability to self-motivate and initiate recreational pursuits; however, when assisted, aided or prompted to engage in activities, the enjoyment and satisfaction gained from participation were clearly apparent. Upbeat moods and spirits continued for several hours following activities and challenging behaviours were significantly reduced.

The Wicking Structured Activity Program had such significant positive effect on Wicking Model Participants; we would recommend that similar programs in the future aim to deliver at least

four half days of activity program per week especially during the initial phases of accommodation transition. The participants exhibited a desire for activities that were focused on outdoor participation and for them to be distributed evenly across the week.

### 5.2.3

#### Dual Diagnoses

The terms ‘dual diagnosis’ or ‘co-morbidity’ refer to the co-occurrence of an alcohol and/or drug use disorder with any other mental health condition.

*“Mental health problems common among people with an ABI include adjustment disorders, depression, anxiety, and drug and alcohol abuse. In addition, the brain injury itself can cause symptoms similar to syndromes such as psychosis and dementia. Most problematically, an ABI can lead to significant problems with impulse control, social skills and self-awareness. These problems may manifest as agitated, difficult, disruptive, inappropriate and/or aggressive behaviour. Such behaviour may or may not be associated with a serious mental illness or disorder”.* Acquired Brain Injury and Mental Illness: Issues Paper (2004) Page 6<sup>110</sup>.

49

In 1997 Government leadership of services supporting people living with dual diagnosis moved from Disability Services to Aged Community Mental Health (ACMH). In March 2001, The Acquired Brain Injury Strategic Plan – Victorian Government Department of Human Services was announced. This led to the establishment of specialist mental health services. Specialist mental health services in Victoria are provided on an area basis, and are often referred to as area mental health services (AMHS). In 2004 an acquired brain injury and mental illness protocol was established between mental health and other services. A key principle in this protocol was, ‘People with an ABI who are assessed as having a co-existing serious mental illness (such as psychosis or a severe mood disorder) have the same right to access AMHS as others with serious mental illness<sup>111</sup>.’

Yet, despite this level of Government recognition at a policy level, this client population continue to be failed by the mental health industry where issues underlying drinking are frequently ignored. Increasingly, a diagnosis of ‘psychosis of intoxication’ is given. Even the most skilled professionals are often unsuccessful in navigating through the bureaucratic red tape that restricts access to appropriate mental health services. Improved understanding and acceptance is required at all Government levels from the policy makers to the level of service delivery on the need for specialist psychiatric support to assist older people living with coexisting mental illness and alcohol related brain injuries.

For people with dual diagnosis, the Austin Health Royal Talbot provides a state-wide consultancy service called the Community Brain Disorders Assessment and Treatment Service (CBDATS). It provides secondary consultation to local generic agencies with the purpose of empowering local services to respond to the needs of these clients. The experience of The Wicking Project was that a CBDATS intervention was the only effective strategy in convincing regional mental health services of the existence of an underlying mental health disorder in our participants, thereby achieving acceptance for service eligibility. Within The Wicking Household major incidents of violence may have been averted with improved access to mental health support.

## The Story of Frank (Aged 55 years)

Frank was referred to The Wicking Project by a HARP (Hospital Admission Risk Program) nurse who held concerns about the inappropriateness of his accommodation at an SRS. At an initial interview conducted to determine eligibility for The Wicking Project, Frank listed 'safety, threats and crap food' as the problems with his housing.

Frank had a long history of alcohol abuse and reported attempting alcohol detoxification programs on more than 100 occasions without success. Frank led a transient lifestyle with no family contact. Diagnosed with Schizophrenia in 1976, Frank's mental health appeared poorly managed. He frequently used ambulance services and regularly presented at hospital emergency departments, seeking Benzodiazepines. On some occasions ambulance services were called twice daily.

Frank entered the Wicking Household in May 2008 with an alcohol dependence of 2 to 4 litres of wine per day. Frank was physically very weak. Initially he was positive and optimistic, often stating that he was grateful for a new start in life.

Whilst living in the Wicking Household, Frank's alcohol consumption decreased dramatically with the implementation of the alcohol program and support of staff. As Frank's physical health improved and he regained his strength he began to refuse support especially involving interventions that were perceived as being too restrictive or controlled. Frank began to object to what he perceived as 'too many house rules' believing they were an infringement on his rights.

Challenging behaviours including verbal aggression and threats of physical violence increased. Conflict with other residents became frequent and it became evident that Frank's behaviour was not conducive to a communal living environment. Frank refused to engage in recreation activities, instead choosing to busk to fund the purchase of additional alcohol. As a result, the frequency of intoxication increased which contributed to augmented behavioural challenges.

Frank began to refuse the depot injections used to manage his schizophrenia and in June 2008 requested a reduction in medication from his treating psychiatrist. The doctor complied with this request without informing or conferring with The Wicking residential manager. This change resulted in a rapid deterioration in Frank's mental state. Confabulations and grandiose delusions were frequent. Frank frequently spoke of working as an undercover police agent for the drug squad, Bob Dylan writing a song about him and often made accusations of theft of personal items. Obsession with legal proceedings relating to an earlier motor vehicle accident and alleged multiple assaults perpetrated by police, were also increasing. This resulted in an admission to the Psychiatric Unit at a major public hospital in June 2008. Despite requests from his treating team and Wicking staff, Frank was discharged without a Community Treatment Order (CTO) – a legal order that set out the terms under which Frank must accept medication while living in the community.

On discharge from hospital, Frank decided to pursue other accommodation as he continued to perceive the Wicking Household as being too restrictive on his lifestyle. In September 2008, Frank moved to a rooming house.

Whilst living independently, Frank's use of Ambulance services and presentations at hospital emergency departments significantly increased once again. Chronology reports from Ambulance Victoria show up to 21 calls a month to ambulance services. After several weeks living independently in the community, Frank contacted Wintringham requesting support. When visited at a rooming house, Frank was found to be in a very poor condition both physically and mentally with suicidal ideation. He was physically incapable of lifting his cask of wine from the floor, living in squalor and emotionally distressed. Frank spoke of his regret in leaving the Wicking Household and requested to return.

After deliberation among all key personnel, Frank was offered a room in the Wicking Household. In December 2008, Frank returned following another admission to a psychiatric unit. Requests for a CTO on discharge were this time heeded.

Again, as Frank's physical health improved and he regained his strength he increasingly rejected support. He again refused to follow house rules and conflicts with other participants escalated. There was a marked increase in the level of social unrest within the household. There was an escalation in the



frequency and severity of verbal aggression, violent behaviour and intoxication among the participants. There was also an expressed lack of trust.

After four weeks Frank had accumulated three formal warnings for behaviours that were in serious breach of the house rules, including threats of physical harm to self, staff and residents and episodes of physical violence toward objects. Frank departed from the household on amicable terms under the care of his Guardian with a recommendation for a referral to Multiple and Complex Needs Initiative (MACNI) and the Brain Disorders Unit at Royal Talbot.

Significant features of Frank's persona that lead to an unsuccessful outcome for the Wicking Project included Frank's strong desire to attain freedom, independence and control which when achieved rapidly led to a spiralling decline in health and wellbeing. This combined with traits of an antisocial personality and a vehement dislike of rules and restrictions were not conducive to an intensive communal support model.

#### 5.2.4

### Cognition, ARBI & Challenging Behaviours

The aetiology of cognitive impairment among older people with extended histories of homelessness is generally multifactorial. There are five principal factors contributing to the presence of impaired cognition, they are; traumatic brain injury, nutritional deficiencies and imbalances, ARBI, age-related dementias and chronic mental illness. Diagnostically, it is almost impossible to definitively differentiate or proportion the relative contribution that each of these components pay toward the neurophysiological and neuropsychological profile of a long-term drinker.

However, in the provision of effective care and support to a client presenting with cognitive deficits of multifactorial aetiology, the differential diagnosis and ascription of each contributory factor is essentially of no additional benefit to the development of an effective behavioural care plan. Apart from the indisputable need to diagnose serious progressive neurological disorders, it is equally as important to determine who the person is as a 'whole being', – to investigate the individual's life story, their history, their behavioural profile and their functional strengths and weaknesses.

Beyond the influence of cognitive impairment, additional factors such as the presence of a personality disorder, a mental illness and past experience of traumatic life events, homelessness, incarceration, abuse and domestic violence can also influence an individual's behavioural profiles. An improved understanding of these contributing factors will lead to the establishment and institution of more effective behavioural support strategies.

ARBI is most commonly associated with impairment to the frontal lobes of the brain.

Neuropsychological studies have shown a significant association between frontal lobe dysfunction and increased antisocial and aggressive behaviour<sup>112</sup>. The Overt Behavioural Scale (OBS) was used in The Wicking Project to determine the frequency and impact of challenging behaviours exhibited by participants. Accumulative frequency scores were collated for all participants over the eighteen month Wicking trial period. These findings are displayed in Figure 25 and are consistent with the behavioural changes anticipated in people living with an ARBI.

Even at its highest levels, the funding tool used by residential aged care facilities, the Aged Care Funding Instrument (ACFI), does not reflect the level of care and funding required to effectively support homeless people/residents, particularly those with high and complex behavioural care needs. The intensive level of care and need for one-on-one support cannot be provided within the

current funding structure and the special needs of residents arising from drug and alcohol abuse are also not provided for under ACFI.

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. Lowered levels of insight and acceptance of a need for assistance can in itself create significant challenges to support staff. Participants would express a desire for freedom, independence and control which when achieved contributed to a decline in health and wellbeing. In addition, participants often demonstrated a vehement dislike of rules and restrictions.

Staff needed to be constantly mindful that challenging behaviour occurred 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. Behaviour management strategies that were proven to be effective for one participant were unlikely to work for another. Individual strategies that could take months of trial and error to develop and refine, could quite suddenly lose their effect. These circumstances could prove quite disheartening for staff, however comfort was taken from the knowledge that new strategies could be built from an ever increasing understanding of the fundamental drivers of the person's behaviour. This slow rate of progress can be likened to the metaphor, 'two steps forward and one step back'.

52

### 5.2.5

#### **Emergency Planning**

Challenging behaviour that occurs as a result of an ARBI can sometimes prove difficult to manage but when these behaviours are exasperated by episodes of acute intoxication, the effects can be extreme to the point of posing critical risk. 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.

It was also very important to establish good relationships and maintain open lines of communication with local police and ambulance services. Information was provided to these services of the high potential for violence presented by resident/s living with an ARBI. Services were also made aware of the policies and procedures in place in the event of an emergency and the recommendation for staff to call emergency services only when a situation of real threat of harm was identified. These initiatives increased the likelihood of a rapid and appropriate emergency service response. In The Wicking Model, police from the local station attended Resident's Meetings in friendly 'meet and greet' sessions with participants as a proactive 'Positive Community Policing' initiative.

### 5.2.6

#### **Service Coordination**

The highly specialised nature of the care required to support this client group required the coopting of support from external agencies. Effective and continued communication and coordination of community service agencies had proven to be one of the greatest challenges to project management. During the investigative phase of The Wicking Project, contact was established with representatives



of some 40 key government and community service agencies. All were provided with electronic copies of the project information and meetings were held with individual service personnel or in group forums (usually staff meetings). Papers on The Wicking Project were delivered to 27 key industry conferences and nine articles were published in professional literature and journals. Yet despite this degree of forward planning, the breadth and scope of involvement with other agencies proved insufficient. This could be attributed to a number of factors including the following:

- There were some services that we had not anticipated would have played a key role in the provision of care and support to participants;
- There were some service branches with which good relationships and rapport were established, only to find that the participant hailed from another service region which had no knowledge of the project;
- Turnover of service staff and changes in key service personnel led to discontinuity in service engagement and a breakdown in established rapport and communication;
- The level of contact that had been established within a particular service (hierarchical level within the organisation) had proven suboptimal for the effective dissemination of project information to key personnel dealing directly with the participants.

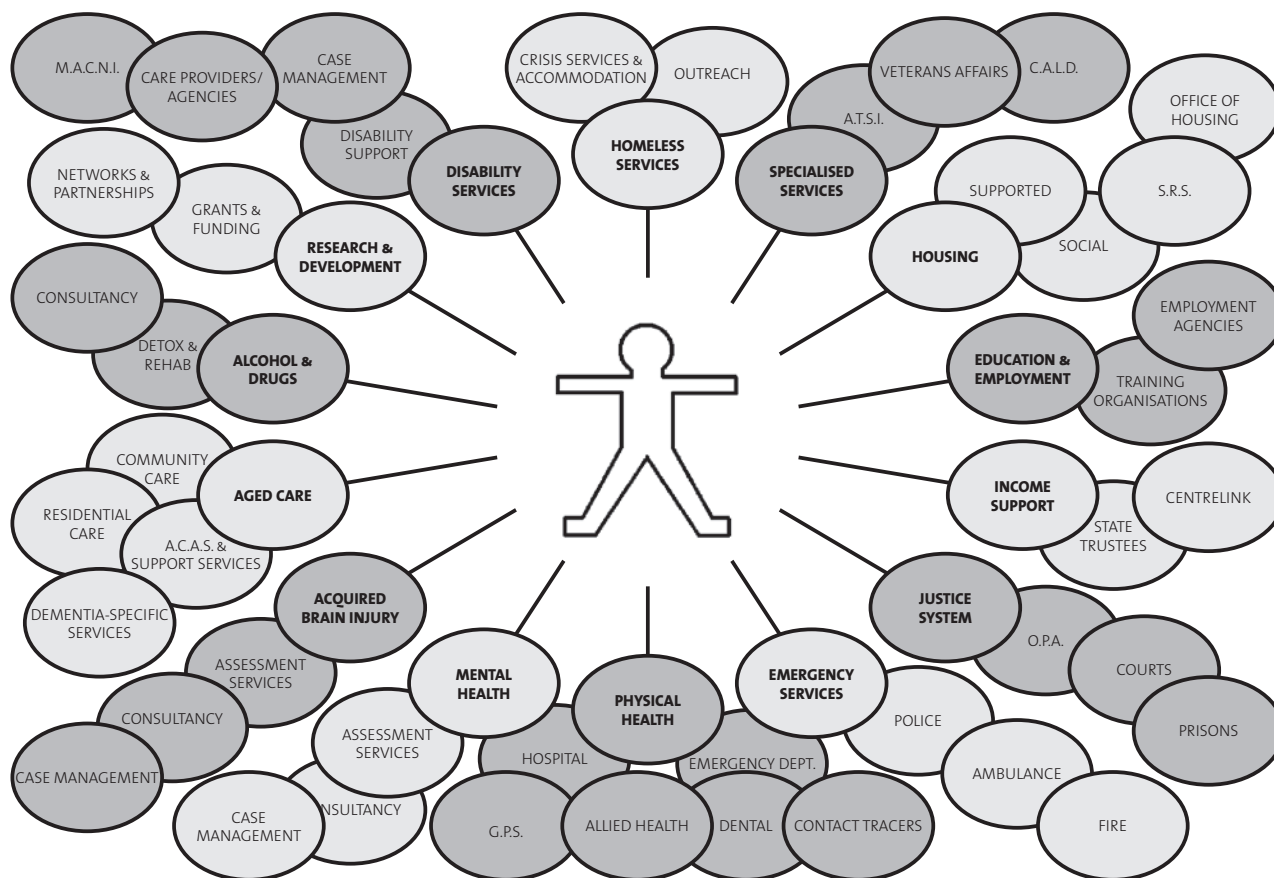
53

Service coordination breakdown became particularly apparent at the commencement of Wicking Trial Participant recruitment. Difficulty was encountered in persuading key agency workers to refer clients to the project. The appeal for referrals was met with suspicion and refutation. This resistance was principally driven by ignorance created by the scenarios listed above resulting in breakdown in the exchange of information within service networks.

Given the focus of the Project was on systemic change, active dissemination played a major factor in project activity. Throughout the implementation of The Wicking Project, in-service training sessions were delivered to some 18 key community service providers including hospital and health care, local and state government, homeless services, emergency services, aged care services and acquired brain injury support services. A significant point of learning elucidated by these interactions was the consistently low level of awareness exhibited on the existence, causes and the effects of alcohol related brain injury among service staff at all staffing levels.

The scope of services with which Wicking participants were engaged was surprisingly vast as Figure 12 shows. Considering the broad array of specialty services available, it is almost inconceivable that a person of similar profile to the Wicking participants could find themselves alone, debilitated and homeless. Yet this does continue to happen for an increasing number of Australians and, all too often, with dire consequences.

**Figure 12** Complexity of Support Services Available to People with Complex Care Needs



54

**5.2.7 Drinking & Smoking Culture**

*Alcohol remains the primary drug of choice among the homeless population (70%). The frequency of alcohol consumption varied by gender and age. A greater proportion of males reported alcohol consumption in excess of four times a week in comparison to female respondents. Furthermore, those who reported alcohol use in excess of four times a week were older. (Lawless & Corr (2005), p16)<sup>113</sup>.*

The culture around drinking and smoking within the older homeless population works to ensure that there is always a way to access additional alcohol and cigarettes if needed. Strategies include:

- Theft of alcohol or consumption of large quantities of alcohol on the premises of bottleshops – e.g. coolrooms, cupboards etc.;
- Theft of goods that can 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);
- Purchase of cheap alcohol sold in large quantities to share;
- Loans in alcohol/cigarettes made for future returns ‘helping out a mate’.

Mutual credit networks and collective consumption works as a strategy where acute and short-term cash shortages are bridged by mutual credit loans. Someone who is broke borrows small amounts of money from his or her friends. After receiving some money these debts are repaid and small amounts are lent to friends in need. This strategy results in expansive money-lending-networks

that do not only serve to bridge acute shortages but also provide a level of financial security. If a given person's capital is partially spread out over a whole group of people in the form of loans, the risk of losing one's entire capital through loss, theft or excessive spending is minimised. Usually each member purchases his or her choice of drinks individually but there are alternative means of acquiring alcohol.

Street Drinking "Schools" is a term used for a group of two or more drinkers who are stationary and drinking together. The term school refers to an informal arrangement of pooling financial resources to ensure that all involved will be able to drink over a weekly period. Contrary to popular opinion, many street drinkers do not sleep rough. Many drink outdoors because it is cheaper than pubs and the members of the group tend to enjoy each other's company. "You're all in the same boat," stated one participant, "You're with people who just wanted to drink with you and not judge you". Most prefer not to drink at home because of loneliness and many wanted to protect their tenancy, especially those residing in dry facilities or those trying to avoid neighbour complaints and the risk of eviction from rental property particularly if the premises come to be used as a drinking den.

This pattern of consumption enables the individual members of the group to satisfy their demand for alcohol even in times with no personal income. Drinkers take turns to buy depending on who claimed benefits ("got paid") that day. In periods of widespread money shortages – mostly by the end of the month, the group-members regularly pool their remaining cash in order to buy and consume alcoholic beverages collectively. It is important to note that all activities linked to the collective consumption of alcohol are subject to the principle of reciprocity. Any member who does not contribute to this give and take is either sanctioned or expelled. A similar, yet considerably less successful process is followed in the consumption of cigarettes.

A consequence of the group culture of lending money and sharing alcohol is that when mixed with the disinhibiting effects of alcohol and the memory loss associated with ARBI, any renegeing on agreements between others in the group is often met with aggression, threats and physical violence. Within The Wicking Household all incidents of aggression necessitating the intervention of police were associated with the consumption of additional alcohol.

### **The Story of Gary (Aged 52 years)**

Gary was referred to The Wicking Project by the manager of a Residential Aged Care facility where he had recently come to live. The manager held concerns for the safety of others at the facility due to Gary's challenging behaviour including verbal aggression, physical violence and frequent intoxication.

Gary had been homeless for more than ten years, having had five changes of accommodation in the preceding three months. Gary had three children but no reported contact with them. He did not have contact with his parents, although reported writing to them occasionally. File notes stated that Gary's parents had bought a house for him many years ago which he had burnt down. These also stated that Gary's parents maintained occasional contact with his service provider to enquire about him, but they did not have any direct contact.

Gary presented at the initial interview as an unstable and volatile man. He was reluctant and cautious when answering questions. Although schizophrenia was noted in the referring documentation and Gary was regularly taking anti-psychotic medication, it later became evident that Gary had never been formally diagnosed with schizophrenia. Gary had significant health and mobility problems and required the assistance of a walking stick. He had a long history of falls, unsteadiness and ataxic gait and spoke of orthopaedic injuries relating to assaults and a motorbike accident. Treatment for health problems was usually received at hospital emergency departments, with an ambulance chronology showing 39 ambulance attendances within the preceding 12 month period. Gary stated 'being with the wrong crowd' and 'being bored' as problems with his housing status.

Neuropsychological reports made observations of Gary being suspicious and guarded. Investigations revealed that Gary had been exposed to violence throughout most of his life since adolescence. The report noted that Gary's self reported alcohol consumption of 'one to two' drinks per day was inconsistent with staff reports of clandestine drinking throughout the day. It also stated that some information provided by Gary appeared to be influenced by grandiose ideation and could not be corroborated.

Within the next couple of weeks, interviewers were informed that Gary had been evicted from the residential care facility at which the first interview took place due to an incident of violence in which he allegedly attacked another frail resident with his walking stick. Gary was now residing in a Supported Residential Service (SRS).

SRS staff reported that since his arrival Gary was frequently verbally abusive towards co-residents and staff. Physical violence remained a concern with ongoing reports of Gary using his walking stick to assault people. Gary reported to interviewers that he was not a perpetrator, but always a victim of this violence.

On a review visit, Gary was an inpatient in a major public hospital where he was admitted as a result of injuries sustained in an assault. He appeared fragile and vulnerable in this environment. Gary's demeanour was the most affable that researchers had ever seen. He was uncharacteristically calm and reflective in answering questions, without aggressive, volatile outbursts. During this visit Gary described his life as a 'great disappointment'.

As the Wicking Project progressed and at each review visit, Gary's physical and mental health and general wellbeing was seen to decline. He was now using a walking frame for mobility due to frequent falls, although the walking stick was always suspiciously close at hand, "Just for defence" Gary would smirk. Interviewers often met (or found) Gary in an outdoor shopping mall where he would spend most of his day seeking alcohol and companionship. Initially he appeared pleased to engage with interviewers but within a short space of time, volatile and aggressive behaviours emerged particularly on discussing his life circumstances. Aggressive ranting about his father holding prestigious positions such as Rear Admiral and a High Court Judge were frequent. Gary reported having had several interactions with police resulting in criminal charges relating to drinking and urinating in public.

During these visits to the mall Gary was observed engaging in sociable banter with "the comrades" (fellow drinkers) who frequented the area. There was an observable camaraderie within this group and an instant suspicion of researchers who were seen to look like "coppers". On one occasion Gary was seen to overstress his frailty in order to evoke sympathy from people passing by. This effort was rewarded with a bag of hot chips. During this interview it was discovered that Gary was indeed particularly frail suffering from a nasty cold. His nose was running endlessly and because he did not have a tissue or a handkerchief he used a snot encrusted hand towel to wipe the debris away. One researcher produced a purse pack of tissues which were gratefully accepted and then placed unopened into a pocket reserved for precious items – not to be used, but revered as a symbol of kindness and compassion.

In view of Gary's rapid health decline and urgent need for support the decision was made to offer him a place in the Wicking Household. Even though the project was in its final stages and therefore only able to offer limited opportunity to achieve significant outcomes, the alternative of doing nothing was considered to be too high a risk for Gary's health. Admission to The Wicking Household was made conditional upon hospital admission to stabilise Gary's physical and mental health and undertake medical detoxification due to the high risk of seizures in the withdrawal from alcohol.

This undertaking had proven to be one of the most exasperating of all Wicking Project experiences as Gary had no formal diagnosis of a mental health condition. Instead he was labelled as having a 'psychosis of intoxication' which deemed him ineligible to receive support from mental health services. After countless referrals, telephone calls and e-mails, all attempts at making this happen appeared futile were it not for the dedication and perseverance shown by a Hospital Admission Risk Program (HARP) case worker and a consultant from the Community Brain Disorders Assessment and Treatment Service (CBDATS). These workers successfully pursued a mental health diagnosis which then enabled Gary to access the mental health services which he so desperately needed.



Unfortunately this all came too late for Gary's move into the Wicking Household. Delays created by bureaucratic red tape and systemic failures meant that the final date for admission to the Wicking Household had expired. Amazingly, to this day Gary remains alive and (not so) well living in the same SRS which can only go to prove the amazing resilience and fortitude of people like Gary.

## 5.2.8

### Harm Minimisation

Harm minimisation was seen as an integral component of The Wicking Model, which ensured that active drinkers, often the most vulnerable of homeless persons, were not excluded from receiving appropriate support. There were three major sources of ethical dilemma associated with the care and management of individuals with drug and alcohol related brain injury (ARBI) and ongoing alcohol dependency. The first involved the balance between an individual's right to autonomy with an acceptable level of protection for themselves and others<sup>114</sup>. The second involved the balance between the provision of individual specialised clinical care, often focused around institutions, and the facilitation of a community-based lifestyle. And the third involved the debate surrounding the practice of abstinence versus carefully managed harm reduction/minimisation strategies especially for long-term drinkers. For these individuals, withdrawal from drugs and alcohol can be a dangerous and sometimes a life-threatening experience.

Harm minimisation is a policy designed to decrease the adverse consequences of substance use without the requirement of abstinence. The theory behind implementing harm minimisation principles stems from the need to accept that a person who has been an alcoholic for the majority of their life, cannot be expected to suddenly attain and maintain sobriety as mandated by the majority of residential care options. The requirement to maintain abstinence within a "dry" residential facility leads to a daily pattern of heavy alcohol consumption immediately prior to entry into the facility, followed by early-morning alcohol-seeking to avoid the symptoms of withdrawal. This behaviour places the individual at significant risk of physical harm through alcohol-seeking activities or while they remain intoxicated on the streets.

A person living with an ARBI most commonly presents with damage to the frontal lobes of their brain characterised by poor decision making and increased impulsivity<sup>115, 116</sup>. This manifests with the person readily engaging in inappropriate or high-risk behaviours in the absence of being able to regulate these behaviours. The behaviours are undertaken despite the individual having previously demonstrated an awareness of the negative consequences of these actions. The brain injury has effectively lead to a dissociation between 'knowing' and 'doing' i.e., whilst the individual is aware of rules and the consequences of breaches, they will act on impulse by exhibiting behaviours that are not guided by this knowledge.

Therefore a person with an ARBI may willingly agree to the terms of a residential agreement whereby they are required to maintain sobriety in order to remain at the facility, however when presented with the opportunity to drink they do not refuse regardless of the consequential risk of losing their tenure. Another influential factor in the adoption of harm minimisation principles is the human rights perspective whereby an individual has the right to make their own life decisions and engage in activities that they consider to be 'simple life pleasures'.

Wicking Model Participants were not prohibited from drinking at the premises. While Wicking staff would facilitate the pursuit of treatment options, this was not necessarily the aim. The principle of self determination underpinned the implementation of the alcohol and cigarette policy whereby the

participant's decisions and choices were pivotal to the development of their individual program. This approach is somewhat aberrant in the fields of aged care and homelessness<sup>17</sup>.

The Wicking Model alcohol policy maintained that alcohol and cigarettes were consumed in 'acceptable' quantities. An acceptable quantity was determined on an individual basis as advised in consultation with medical and specialist services. Excessive drinking was defined as such that resulted in behavioural disturbances which impacted negatively on other residents, staff or on the health status of the drinker. Alcohol could be consumed by participants in their rooms but smoking was only permitted in designated outdoor areas largely for occupational health and safety reasons.

One major factor that influenced the development of alcohol and cigarette programs was whether the individual's finances were being managed by an administrator. For participants with an administrator, an arrangement was made to regulate access to funds available for the purchase of additional alcohol and cigarettes exceeding the quantity agreed to in the alcohol and cigarette budget. Assistance was then provided to participants to ration their alcohol and cigarette allocations to ensure that they will last from one pay day to the next. Participants selected the times that they preferred their drinks and cigarettes to be offered and could adjust their allocations according to these preferences.

58

Wicking Model Participants without an administrator were encouraged and supported to manage their alcohol, cigarettes and finances themselves. However, for many, substance dependence and long established patterns of overindulgence almost inevitably resulted in less successful outcomes than would have been achieved through a more structured program. Many participants came to recognise this through the realisation that other participants on programs were continuing to enjoy a drink and a cigarette long after their money and supplies had run out. This invariably led to an uptake of the suggestion to trial an alcohol or cigarette program.

Alcohol and cigarettes were purchased and decanted into the appropriate daily quantities. Staff administered the supplies using a medication treatment chart. All staff were instructed to adhere precisely to the program. At the time of administration, staff would always give the participant the choice as to whether they would like to receive their allocation. In the event that participants missed their scheduled allocation, this was then carried over to the next administration time. This was found to occur with regular consistency during day-time hours as individuals were encouraged to participate in meaningful community activities which were undertaken away from the home over extended hours. Participants could accumulate missed drinks to a maximum of 3 drinks on the one occasion: however, missed drinks were not carried over to the next day.

### **The Story of Wayne (Aged 49 years)**

Wayne was referred to the Wicking Project by his case manager. He had been a client of the Multiple and Complex Needs Initiative (MACNI) for approximately twelve months. Wayne had entrenched patterns of transient accommodation interspersed with periods of homelessness. A history of aggression and violence had seen Wayne banned from multiple services. At the time of his referral he was living in private rental accommodation shared with four others, one of whom held the lease. Wayne had initially been living in the garage at the property and then moved into the house, although he would often 'sleep rough' due to conflict with housemates. His accommodation was not secure, with an impending eviction due to rent arrears. Arranging an initial interview and subsequent review meetings with Wayne proved challenging with frequent cancellations due to his cyclic alcohol binges which could last for several weeks. A multitude of services along with changes in key personnel regularly hindered efforts to meet with Wayne during periods of sobriety, but when these 'windows of opportunity' presented, interviewers seized them.



On initial interview, Wayne appeared anxious but pleasant. He was well groomed and welcomed interviewers into his tidy and well kept home. Wayne reported that he had previously been married but was separated from his wife. He had fathered twins in this relationship and was also stepfather to his ex-wife's child. Wayne stated that he maintained irregular contact with this family and proudly produced framed photographs. Neuropsychological reports stated that Wayne had 14 children to four different partners, although this could not be corroborated.

Wayne first experienced homelessness at the age of 13 years. Prior to this he had lived with his grandmother after leaving his parental home because of arguments and reported abuse. Wayne's parents were reported to have consumed excessive amounts of alcohol and were verbally abusive. Wayne did not maintain contact with his elderly parents or siblings. Wayne witnessed his mother attempt suicide on several occasions. He was principally employed in tailoring and labouring trades with his last job terminating approximately 10 years ago. Wayne's finances were managed under an administration order by State Trustees.

Wayne had been imprisoned for 9 months some two years earlier for an undetermined crime. It was reported that he attempted suicide by cutting his wrists whilst incarcerated. Another document referred to Wayne ingesting poison and several other incidents of alcohol and drugs/prescription medication overdoses. All of these incidents were self-reported as being accidental. A severe leg fracture sustained in a drunken fall was compounded when Wayne repeatedly hack sawed off his plaster cast claiming it to be a hindrance.

Wayne repeatedly expressed a desire to maintain total abstinence with a history of between 100 and 150 admissions to residential detoxification programs. His first admission to a detoxification facility occurred at the age of 22. He estimated that his alcohol consumption ranged from 2 cans of beer up to 2 casks (8 Litres) of wine per day, stating that he drank beer regularly but binged on wine. Wayne considered his drinking to "definitely" be a problem and spoke of the falls and blackouts he had experienced while intoxicated. Wayne smoked an average of 11 cigarettes a day. He also reported previous occasional use of LSD and marijuana.

Wayne's primary health issues included chronic alcohol use; management of physical health needs (including adverse withdrawals when Wayne decided to suddenly cease alcohol intake); repeated presentations to Hospital Emergency Departments; frequent use of ambulance services; and non-compliance with medications. Wayne had sustained multiple injuries as a result of being hit by a tram, falling down stairs, collapsing in the street and being assaulted on numerous occasions.

Wayne stated that he frequently felt depressed, anxious and nervous (primarily about health concerns). Wayne described his life as "confusing" and said he tried "not to dwell on the past". Occasionally Wayne would exhibit episodes of thought disturbances, paranoia, delusions and confabulation. He had difficulties maintaining appropriate social relationships with reports of stalking people with repeated phone calls as well as inappropriate interactions with staff.

Although a room was held at The Wicking Household for many months, continued delays hindered Wayne's opportunity for admission. Wayne did not present to four successive attempts for admission to medical detoxification, a necessity due to the high risk of seizures. Unfortunately the move into the Wicking Model did not eventuate due to Wayne's indecision combined with bureaucratic red tape and systemic issues.

Despite the multitude of services involved, Wayne continues live a life of transience and turmoil.

## 5.2.9

### Participant Life Cycles

A cyclic lifestyle pattern was noted among many Wicking Project Community Participants. Cycles following 3 to 6 monthly patterns were observed during which time participants transitioned through episodes of extreme hardship followed by periods of stabilisation.

The 'hard times' were usually accompanied by massive or repeated alcohol and other drug binges leading to acute mental and/or physical health crises. This then led to periods of engagement with emergency and crisis support services. During this time, the participant's health and strength improved and they began to feel empowered to 'take control' of their life and return to a lifestyle offering greater levels of independence. Unfortunately, in the presence of a brain injury, compromised levels of insight and an inability to inhibit high risk behaviour, often led to rapid deterioration in health and wellbeing. And so the cycle is repeated. As a result of this sequence of events, every time a participant completes each cycle, the likelihood of them being able to 'bounce back' or assume previous levels of functioning is compromised as chronic illnesses and accumulative damage to body organs begin to take their toll.

#### 5.2.10

#### Other Drugs

60

Substance abuse (abuse of drugs and/or alcohol) among older adults is increasing<sup>118,119</sup>. European estimates suggest the number of people aged 65 and over with substance abuse problems or requiring treatment for substance abuse disorders will more than double between 2001 and 2020<sup>120</sup>. Many older people of today are using drugs because they did so when they were younger, and their patterns of consumption have changed very little as they have aged<sup>121</sup>. The combined consumption of alcohol and other drugs can have some atypical effects on the body.

Acute doses of alcohol (e.g. binges) may inhibit a drug's metabolism by competing with the drug for the same set of metabolising enzymes<sup>122</sup>. This interaction prolongs and enhances the drug's availability, potentially increasing the risk of harmful side effects from the drug. Chronic (long-term) alcohol ingestion may activate drug-metabolising enzymes, thus decreasing the drug's availability and diminishing its effects. After these enzymes have been activated, they remain so even in the absence of alcohol, affecting the metabolism of certain drugs for several weeks after the cessation of drinking<sup>123</sup>. Therefore, chronic drinkers may need higher doses of some medications than those required by non-drinkers to achieve the same therapeutic/euphoric effects. Enzymes activated by chronic alcohol consumption can transform some drugs into toxic chemicals that can damage the liver or other organs. Alcohol can also magnify the inhibitory effects of sedative and narcotic drugs at their sites of action in the brain.

The use of illicit drugs by older adults is largely unacknowledged but will increase as the general population of many developed countries ages, and drug users continue to use drugs. Many poly-drug users do not see their drug use as a problem therefore do not recognise any need to change. Inappropriate polypharmacy including co-alcohol use, especially in an elderly person who is drug dependent but not aware of their problem due to limited cognitive competence, presents one of the most challenging problems to aged care service providers in the future. The harm minimisation interventions employed for alcohol addiction, being a licit drug, does not raise as controversial a moral debate as the prescribing of cocaine, for example.

One such poly-drug user was a participant in the Wicking Project trial and the outcomes for this participant proved least successful of all Wicking Model Participants as they were unable to recognise the true consequences of their drug use. For this participant, once the hazardous and harmful alcohol and drug use were identified, a less intensive behaviour management strategy (i.e. involving less vigilance and intervention) proved to be more effective in the delivery of care and support.

Tobacco use is a leading cause of death amongst individuals aged 60 years and older (e.g. heart disease, pulmonary disease)<sup>124</sup> and associated with an increased loss of mobility in both men and women.<sup>125</sup> In a 2004 study, cigarette smoking was found to both exacerbate alcohol-induced damage as well as independently cause brain damage<sup>126</sup>. Smoking is more prevalent in older problem drinkers, with estimates of 60% to 70% of older male problem alcohol consumers smoking a pack per day<sup>127</sup>. Unlike other drugs, use of tobacco is rarely concealed.

After a lifetime of smoking, older persons may be reluctant to quit because, unlike younger age groups, they see the damage as already done. There are some that consider smoking to be one of the few life pleasures left to the elderly person. However, contrary to common belief, smoking cessation in the older person can lead to substantial improvements in health<sup>124,128</sup>, including a likely decrease in the risk to cognitive functioning<sup>129</sup>. The problem is that an older person living with an ARBI most likely has neuro-behavioural traits which would deem them unlikely to cease smoking in much the same way as they are unlikely to stop drinking.

Concurrent ageing and the use of illicit drugs present unique problems for older people, particularly in terms of the chronic effects of drug use on ageing brains and bodies<sup>130</sup>. The Wicking trial demonstrated that the behaviours exhibited by a person who engaged in illicit drug-use were markedly different to those who are addicted to alcohol and tobacco alone and therefore possess an entirely different set of care needs. Although this observation was based on a sample of one, caution must be exercised with the inclusion of individuals with illicit drug addiction into a model designed specifically to support people living with an ARBI.

### **The Story of Jack (Aged 54 years)**

Jack was referred to the Wicking Project by an advocate guardian from The Office of the Public Advocate. Jack lived alone in the community in a house owned by his mother. Estranged from his mother and most of his family, Jack spent the best part of each day seeking alcohol and other drugs. A virtual revolving door of over night stays by desperate and opportunistic mates had left the house barren and unclean.

Jack was employed as a public servant for 18 years until the death of his wife from cancer in 1996. He had not worked since. Jack remained particularly stressed over his wife's death stating that he "missed her everyday". Jack had five children from this marriage. Child Protective Services had removed Jack's youngest daughter from his care in December 2007 as his home was considered an unsafe living environment. Two of Jack's other children were reported to have mental health, drug and alcohol issues. Jack listed 'isolation' and 'too many reminders of the past' as the main problems associated with his housing status.

On the morning of initial interview Jack presented as a pleasant, open and honest man. His appearance surprisingly belied his 53 years of age which Jack attributed to his Mediterranean genes. He appeared intoxicated and confirmed to interviewers that he had already consumed a considerable amount of alcohol prior to our 10 o'clock meeting. He estimated that his average level of alcohol consumption was twelve drinks per day. Jack also reported poly drug use including marijuana, speed, cocaine, LSD and any other drugs that he could acquire.

In the week prior, Jack had been hospitalised as a result of a near-fatal overdose. Jack smoked over 60 cigarettes a day. He had a poor diet, eating once every couple of days. Reports show that Jack had a long history of depression, heavy drinking and gambling with a previous diagnosis of psychotic depression with chronic suicidal ideation (although no history of self harm) and severely disturbed sleep patterns. Jack said that he felt "down" and stated that he expected to "be dead within a year".

A Department of Human Services (DHS) worker supporting Jack reported that the DHS were considering sectioning Jack under 'Section 11 of the Alcoholics and Drug-dependent Act' due to serious concerns for

his safety and that of others. Issues of concern included recent hospital admissions and criminal charges resulting from fights with neighbours and incidents of fire lighting. Unsafe sexual practices and the sharing of needles through IV drug use were also of concern particularly in view of the presence of a communicable disease (in 2006) requiring the involvement of Contact Tracers (a Government service responsible for ensuring public safety from sexually transmitted infections). Jack's case manager advised that Jack engaged in occasional recreational drug use, particularly when alcohol was unavailable.

Jack moved into the Wicking Household in May 2008. Initially he appeared to benefit from the intensive support with improved health, weight gain and overall demeanour. Seeing Jack sit contentedly at the kitchen table of his new home eating fruit from the fruit bowl was a highlight for staff.

The environment of the Wicking Household appeared to foster more frequent contact from Jack's children. His youngest daughter visited on several occasions and remarked to staff on how well her Dad appeared. A second daughter also gave positive feedback to staff. Visits from a third daughter brought new issues of concern as she herself had alcohol, drug and mental health problems. Staff soon came to suspect that this daughter was supplying her father with drugs and alcohol. Jack was fiercely protective of his daughters and on occasions when staff intervention was required during visits from this daughter, incidents of verbal aggression and threats of physical violence were perpetrated by Jack.

It became evident that Jack was a vivacious poly drug user who presented significant risk to himself and others through impulsive behaviour which increased with additional drug and alcohol intake. Jack's obsession with drug seeking intensified over the ensuing months. Jack spoke openly of his need to be constantly substance affected stating 'I'll take 'anything I can get'. And that he did, with staff eventually solving such mysteries as Jack's multicoloured hair – he'd been chroming (inhaling the contents of spray paint containers).

In addition to this, Jack displayed unpredictable aggressive and challenging behaviours that varied with each substance that he abused – for example increased aggression occurred while 'coming down' from ICE (crystal methamphetamine). Jack's activities had also attracted drug-associated individuals to the Wicking residence. On several occasions Jack surrendered a kitchen steak knife hidden in his room which he held in fear of unwanted night time visitors to his bedroom window.

Jack had very poor impulse control and displayed no desire to reduce his drug and alcohol consumption. Staff and service providers came to suspect that Jack was dealing drugs as he did not have the income to sustain his use. Jack also supplied other Wicking residents with alcohol and drugs which often turned into room parties. This inevitably led to major incidents of aggression and violence.

With encouragement from staff, Jack agreed to attempt formal medical detoxification but was soon evicted from the unit as a result of 'dealing in substances' while in residence at the detoxification facility. The longest recorded period of abstinence from drugs for Jack was three days. Jack took great pride in this achievement and spoke of this often.

The requirement to extensively adapt the Wicking model to support Jack's other drug-related needs and the high level of risk associated with his behaviour, finally lead to the decision that Jack's participation in the project was compromising the validity and viability of the study. This, in conjunction with the fact that after five months of intensive Wicking intervention there was no evidence of even a minimal decrease in his drug-related behaviours, led to the decision that Jack should exit the Wicking Project Trial.

Following his departure, Jack was observed to have lost a significant amount of weight and several front teeth. His appearance eventually surpassed his age. He was actively engaged in intravenous heroin and other drug use. He stated that he had "regrets" about no longer living in the Wicking residence and that he, "took advantage of it".

And yet in spite of all this, he was still an endearing man with a cheeky smile.



## 5.2.11

**Neuropsychological Involvement**

Although costly and lengthy, a neuropsychological assessment provided the most valuable tool in tailoring the most effective behaviour intervention for Wicking Model Participants. Neuropsychologists use scientifically validated objective tests to comprehensively evaluate cognition, mood, personality, and behaviour. An important outcome of this testing was the interpretation of the results to inform treatment or intervention planning but also to provide a valuable insight into the capacity or potential of the individual to change or modify their behaviours. An intensive ARBI support model such as Wicking would not be successful without ongoing, high quality neuropsychological input.

A specialist Neuropsychologist/Case Manager with a dedicated skill set was recruited to support The Wicking Project Trial. A competitive tender process was used to select an independent service provider that specialised in providing Neuropsychology and Occupational Therapy services to assist people living with an acquired brain injury.

63

The general roles and responsibilities of this provider included:

- Undertaking pre- and post-trial neuropsychological assessment of all Wicking Project Participants;
- Establishing individual participant behavioural care plans and drinking programs at the commencement of residency;
- Delivery of initial and ongoing specialist training on Alcohol Related Brain Injury and behaviour modification strategies to Wicking Project staff;
- Supporting staff in participant behaviour management planning and strategy implementation;
- Liaising with staff on the review of care plans;
- Providing counselling support to staff and participants;
- Attendance at participant and staff meetings;
- Advise on research methodology and analyses;
- Ongoing input into operational design.

The neuropsychologist maintained an ongoing supportive role for participants and Wicking Project Staff throughout the duration of the trial.

## 5.2.12

**Participant Selection Protocol**

The one consistent factor in the process of identifying, selecting and recruiting eligible participants for The Wicking Project was the chaos that harried their lives. On multiple occasions the researchers were faced with often insurmountable obstacles preventing eligible and willing participants from taking up vacant positions within the Wicking Household. Frequently these obstacles were created by bureaucratic red tape and processes hindering access to services or information crucial to the effective delivery of appropriate care.

It was never anticipated that The Wicking Model of Care would entirely suit all participants. A “one size fits all” approach to such a highly specialised model would be destined for failure even with the adoption of individually tailored care plans. Participant traits or characteristics that were less conducive to this model 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);
- An overwhelming desire for freedom, independence and control which when achieved rapidly lead to a spiralling decline in health and wellbeing;
- A vehement dislike of rules and restrictions;
- Ongoing addictions to other drugs (not including tobacco/cigarettes).

### 5.2.13

#### **Disability Support Services**

People with acquired brain injury are eligible for support under the Disability Support Act, since it was enacted in July 2007; however, their access to this support system is incredibly ad hoc (please refer to Figure 12 – Complexity of Support Services Available to People with Complex Care Needs). The Disability Support Register (DSR) is a system that records information about a person's need for support so that when services become available they can be allocated in a seemingly fair, transparent and efficient way. Individual Support Packages (ISPs) are disability service funds that are allocated to a person to meet their disability related support needs. Applications deemed eligible to be placed on the DSR follow a long and tedious process. Supporting documentation must be obtained from a number of sources including the person's GP or a neuropsychiatric assessment in confirmation of the presence of a disability. ISPs are finite, and once fully allocated within the region the individual must wait for a package to become available. Further, if there are changes to a person's needs which cannot be met within a support package, the person must make an application to amend the Register to have these 'new' needs met.

64

It was the experience of The Wicking Project that successful navigation through this process required a minimum 6 months of administrative process (approximately 20 hours were spent in preparing each DSR application). Applications demanded the involvement of key personnel who possessed an integral knowledge of not only 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. Despite this level of dedication many applications were returned up to four times for review and further clarification. Meanwhile, these clients were living under circumstances of such significant risk that the balance between life and death was extremely tenuous.

### 5.2.14

#### **Aged Care Assessment Service**

Under the Aged Care Act 1997, access to residential aged care services is gained through assessment for eligibility by Aged Care Assessment Teams (ACAT). Despite recent legislative changes to include older homeless people as a 'special needs' group under the Aged Care Act 1997, this population still experience great difficulty gaining access to appropriate residential aged care. This is partly due to a dearth of residential care places available that are equipped with the expertise required to support the needs of this client group but also due to discrimination arising from the stigma attached to a homeless person.

The working relationship between Wintringham and some ACATs has generally been positive and effective in reaching decisions made in the best interest of the client. However, differences in the service delivery styles adopted by not only individual ACAS team members, but also between different service teams, can result in unnecessary delays in clients receiving the appropriate level



of support. Much of this inconsistency related to the interpretation of the eligibility criteria used to determine the most appropriate level of support.

Throughout the implementation of The Wicking Project a furtive reluctance was encountered by some ACATs to refer those identified as being prematurely aged to residential aged care. This reluctance was partly driven by increasingly stringent recommendations on the minimum cut-off age for eligibility to aged care, but also due to a limited understanding by some ACATs on the special needs of the elderly homeless.

#### 5.2.15

### Capability & Capacity

The Wicking home had four bedrooms and therefore the capacity to house four participants. This guided The Wicking Model toward a one-to-four carer: participant ratio; however, in our contingency planning we did not anticipate the long periods of bed-vacancy that occurred. A number of factors contributed to this occurrence including the unpredictable nature of participant lifestyles, screening for eligibility and poor cooperation and communication between referring agencies and service providers.

In the evaluation of this project, it is important to consider the capability of the Wicking Model of Care with regard to the number of people that could feasibly be supported together in the one residence at the one time. There are a number of qualifying factors that can influence this determination, namely the:

- Ratio of staff available to provide support;
- Skill level of the staff providing support;
- Level of demand present at any particular point in time as determined by the cumulative complexity of need exhibited by the participant population (physically and behaviourally);
- Conduciveness of the environment in which the care is delivered; and
- Quality and responsiveness of specialist auxiliary services e.g. mental health.

The Wicking household ran relatively well when one staff member was responsible for supporting four residents at the one time (1:4) plus two additional days of direct care support provided by a recreation support worker each week. However, it did appear that The Model operated more effectively at a ratio of 3:1. With this ratio, the household ran with greater efficiency with a marked reduction in the incidence of violent or aggressive behaviour. This observation must be premised on the circumstance that all residents were newly admitted to the home at approximately the same time and that participants recruited into The Wicking Model, particularly on the first intake, exhibited some of the most extreme of challenging behaviours.

As discussed later (Chapter 5.4.15 Behavioural Changes over Time) a peak in challenging behaviour characteristically occurred around the three-month mark following admission. An implication of this was the extremely high accumulative level of demand placed on staff at a time when all residents experienced simultaneous peaks in the intensity and frequency of challenging behaviour. This placed considerable strain on staff time and available resources, yet alone the consideration of increased risk to personal safety.

A staff ratio of 1:4 could therefore be effectively sustained if the admission of new participants were staggered in such a way as to avoid co-occurring peaks in behaviour. In consideration of an environment in which more than 4 participants exhibiting highly challenging behaviour could be housed together, it is cautioned that even if appropriately high staff ratios are ensured, issues

pertaining to the drinking culture discussed previously (Chapter 5.2.7 Drinking & Smoking Culture) could present considerable barriers to maintaining household stability.

#### 5.2.16

### Gender Specificity & Sexuality

Throughout the development of The Wicking Project Trial we held the belief that the inclusion of a female participant into this type of residential environment would introduce an element of unacceptable risk of sexually inappropriate behaviours. However, through the implementation of the trial it had become apparent that the significance of this risk had been overestimated. This combined with the disproportionately large number of referrals received for women to participate in the project, indicates a scarcity of appropriate residential support options for aging women living with challenging behaviours and alcohol related brain injury.

Often associated with alcohol-related frontal lobe brain injuries is an inability to retain and use new information and knowledge; thereby challenging the successful uptake of strategies promoting safe sex practices and increasing the risk of sexually transmissible disease.

66

#### 5.2.17

### Staff Training & Support

Wicking Model Participants established strong and trusting relationships with direct care staff who in turn were supported by the milieu and by others (manager, neuropsychologist, and other direct care staff). This allowed direct care staff to maintain a calm and objective relationship with participants at all times and consistently and appropriately manage complex and testing behaviours. In order to respond appropriately to the diverse needs of participants, staff demonstrated a high level of flexibility and spontaneity while striving to be as comprehensive as needed in order to effectively engage.

Most Wicking Project care staff were recruited from within Wintringham services and therefore already possessed a broad knowledge and experience in working with people presenting with ARBI and challenging behaviour. Staff were highly trained, closely supervised, supported and monitored and encouraged to continue to engage in ongoing professional development. The importance of staff training in a program such as this cannot be understated. Appropriate recruitment, induction, supervision and continuing professional development are vital if the investment in staff training is to be effective. Residential aged care residents report that it is the approach and attitude of frontline care staff that has the greatest influence on their level of satisfaction with their accommodation<sup>131</sup>. Without skilled and motivated staff, an effective residential program would not be able to continue to provide high quality specialist care and support to its residents<sup>132, 133</sup>.

All Wicking staff attended an initial two day training module followed by three subsequent one-day follow-up training sessions several months apart. The training module was specifically developed for Wicking Project staff and delivered by neuropsychologists specialising in acquired brain injury. The training modules included anatomy of the brain and the function of areas of the brain, clinical and cognitive-behavioural profiles for acquired brain injury (ABI), alcohol related brain injury (ARBI), traumatic brain injury (TBI) and dementia. The syllabus also covered the principles of rehabilitation and management of cognitive-behavioural problems (based on World Health Organisation's (WHO) framework of disability, provided by the International Classification of Functioning (ICF)<sup>134, 135</sup>). As well as standard work place supervision and support, ongoing staff support counselling and

debriefing was provided by the specialist neuropsychologist in a group environment at staff meeting/training sessions, case conferences or on an individual basis as required.

In the absence of effective policies and procedures around staff support, the stress of working closely with clients frequently displaying challenging behaviour can take its toll. This can result in high levels of staff fatigue, “burnout” and turnover. Occupational health and safety is a major concern for staff when dealing with residents who demonstrate these challenging behaviours. Poor staff retention can ultimately have a negative impact on the quality of life for clients<sup>136</sup>. Being frequently passed from one key worker to another can result in increases in challenging behaviour and decreased levels of confidence and trust influenced by previous negative life experiences, particularly so for disempowered people<sup>137</sup>. Staff rotation must be balanced with the potential for break down in rapport and consistency between staff and residents.

Homeless people with high and complex care needs generally do not have access to family members or friends, which can result in extremely high emotional needs. This void is usually filled by residential care staff. Wicking staff were therefore recruited for their exceptional people skills and commitment to a job that would often be mentally and emotionally draining. The recruitment aims were to recruit staff who were mission-driven, competent, compassionate, non-judgemental and willing to work in situations that were not always ideal. The Wicking Project staffing procedure implemented a number of recruitment and retention strategies in recognition of the significant contribution that staff made to the quality of participants’ lives.

67

#### 5.2.18

### Individual Care Plans & Specialist Case Management

Because Wicking Project Participants had experienced troubled and/or disadvantaged past histories, individual care plans reflected strategies designed specifically to manage the characteristics and behaviours associated with these lifestyles. Challenging or difficult behaviours were managed in a collaborative approach involving the individual participant, staff and where applicable, in consultation with an advocate guardian, neuropsychologist or an external expert advisor. Individual behaviours were initially thoroughly assessed and continually monitored and care plans modified through effective care plan strategies. A large section of the care plans were dedicated to the management of challenging and difficult behaviours.

The interventions and support offered by direct care staff and other personnel involved in the case plan (e.g. neuropsychologists, medical specialists) formed the basis of the outcomes-focused Wicking Model, designed to assist participants to achieve stability and to develop the skills to enable them to progress toward greater levels of independence. A key determinant of healthy ageing was promoted through engagement in productive and meaningful activities. Participants were supported to strengthen their skills to support efforts to achieve and maintain good health.

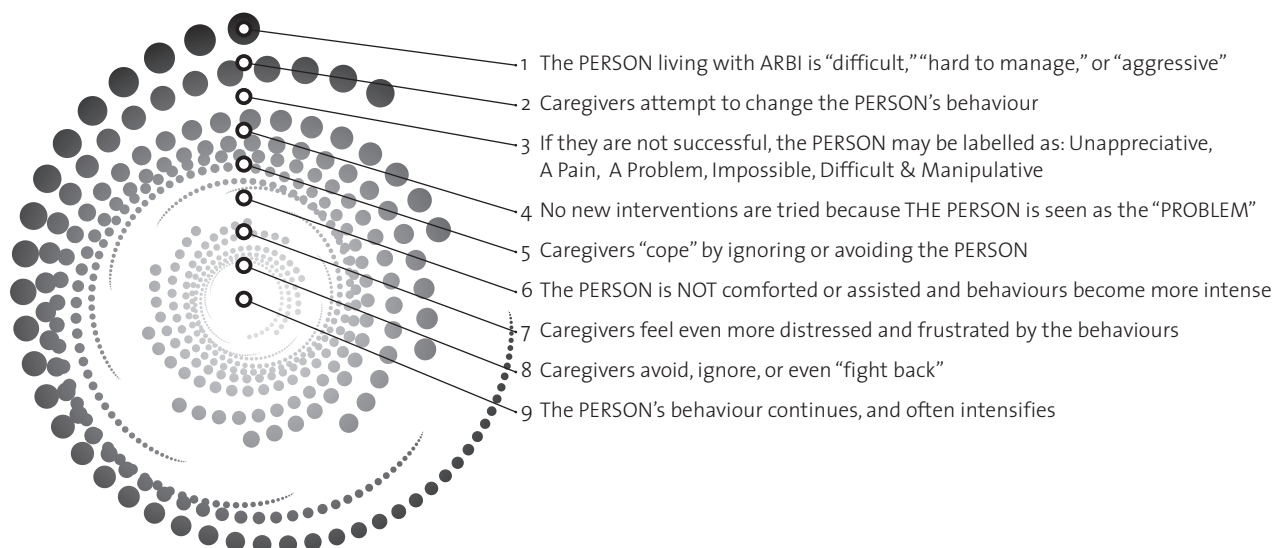
#### 5.2.19

### The Spiral of Negativity

A significant point of learning for care staff supporting The Wicking Model Participants was achieved through the recognition that negative perceptions, views, and labelling of older persons living with an ARBI can contribute to the development of a cycle of mutual distress. Not only does the person with an ARBI have unmet needs that continue to cause underlying distress (compromising their quality of life), but caregivers also suffer: from feelings of frustration,

incompetence, anger and resentment. These feelings, perceptions and labels can contribute to a downward spiral of negativity in care practices (see Figure 13).

**Figure 13** The Downward Spiral of Negativity Affecting People Exhibiting Challenging Behaviour<sup>138</sup>



68

People living with an ARBI can behave or communicate in ways that could be perceived as personally hurtful or offensive to caregivers, service staff etc.. In the absence of appropriate knowledge and skills, these caregivers are not able to recognise that the behaviour was not intended to be personal, but rather a reflection of the person’s internal state and their inability to respond appropriately due to the presence of a brain injury.

Caregivers must therefore be attuned to early changes in their own behaviour, and that of others, which can indicate avoidance or building levels of negativity toward a person exhibiting challenging behaviour. Some subtle changes can include not smiling or avoiding eye contact, and less subtle changes include avoiding physical contact and avoiding conversation. If left unchecked the consequence of these responses can lead to increases in the frequency or severity of challenging behaviour and higher levels of caregiver distress.

#### 5.2.20

### Project Partnerships

At a pivotal stage of the Wicking Project Trial, at the commencement of participant recruitment and assessment, a major project partner withdrew their participation from the project due to funding shortfalls within their own budget. This situation necessitated significant adjustments to project grant funding allocations and disruptions to project timelines. A hard learned lesson in the formation of partnership agreements for major projects such as The Wicking Project was the importance of determining the capacity of partner organisations to realise and maintain service agreements, especially in the provision of fiscal or “in-kind” support. In the project development stage, careful consideration must also be given to the risk of a major project partner withdrawing their support and preparing contingencies for such occurrences.

### 5.2.21

#### The Wicking House Rules

The Wicking Model Participants played a significant role in developing the house rules aimed at achieving a more stable and cooperative living environment for all concerned (Figure 14). Repeated behaviours in breach of house rules resulted in the drafting of individual behavioural contracts referred to as Resident's Agreements, which specified acceptable behaviour and ramifications of failing to adhere to these. These Agreements were negotiated between the participants and the facility manager and were used as a tool to facilitate behaviour modification through strategies aimed to achieve mutual advantage. For those participants who could not understand or retain information, staff provided supervision to identify patterns of behavioural indicators or potential triggers for challenging behaviours and implemented proactive strategies in order to negate or minimise the severity of the behaviour. Both successful and unsuccessful intervention strategies were noted on individual participant care plans.

Figure 14. The Wicking House Rules.

#### Wicking House Rules

These House Rules apply equally to all residents, staff and visitors.

- Treat others with respect at all times
- Do not enter other resident's rooms unless invited
- You must always notify care staff when you leave the house
- You will need to inform staff of where you plan to go and when you expect to return
- Visitors are not permitted before 10am and after 10pm
- No sleep-overs are allowed
- Visitors are not permitted to bring alcohol or other drugs into the house
- You are responsible for your own house keys – a replacement fee will apply
- Smoking is not permitted indoors
- Extra alcohol is not permitted in the house
- The sharing of alcohol and cigarettes is not permitted
- Illegal drug use is not permitted in the house
- Loud noise is not permitted before 10am or after 10pm
- The telephones are not to be used between the hours of 9pm and 9am unless in an emergency

### 5.3

#### Memorable Wicking Moments

##### 5.3.1

#### Wicking Barbeques

Barbeques in The Wicking Household became a regular occurrence and were enjoyed by all. Somehow the holding of tongs, turning of cooking meat and the smell of charcoal-filled smoke brought back to The Wicking Model Participants recollections of how things used to be in better times. Of course JR the Dog was always scouting around underneath the barbeque ready to snuffle up any wayward snags.

## 5.3.2

**Christmas 2008**

The Wicking House was festooned in decorations and the bottom of the Christmas tree laden with gifts. The participants attended no less than four pre-Christmas parties, including one at which two Wicking Participants dominated the Karaoke microphones bellowing out to the lyrics of Elvis and Pat Benatar. The celebrations culminated in a traditional Christmas lunch shared with the Rooming House neighbours hosted in The Wicking residence. "This Christmas was bloody fantastic," exclaimed one participant. "I've not had a better one since I was a little boy."

## 5.3.3

**Radio Interview**

Radio 3CR Community Radio invited The Wicking Model Participants to an interview to discuss their life experiences. The Roominations program is a radio broadcast specifically for homeless people. Two participants agreed on the proviso that they could input the type of questions that they would be asked. The radio hosts met with the participants in their home a week prior to the interview to appease apprehensions. This preparation contributed to an enjoyable and rewarding experience on the day of the interview. Both residents took great pride in this achievement and widely distributed the CD.

70

## 5.3.4

**The Wicking Holiday**

A small overnight holiday was undertaken by two Wicking Model Participants and JR the Dog in a private cottage in Whittlesea. The Wicking recreation worker and a Personal Care staff member also attended. The participants enjoyed 4-wheel driving 'bush bashing' in a small open top Suzuki. One participant screamed and the other held his breath and gripped the dashboard as they drove over the 'drop off'. This was soon followed by uncontrollable laughter and pleas of "let's do it again".

## 5.3.5

**Music Therapy?**

A Wicking Model Participant had mentioned how his guitar had been stolen in the SRS where he had previously been living. A staff member loaned him a guitar in the belief that music playing would serve as a positive recreational activity. Unfortunately, this did not pan out as expected with the guitar being used to busk for money. This money was consistently used to purchase large amounts of alcohol and other drugs which were hastily consumed by the participant and shared with other Wicking Household participants.

**The Story of Mark (Aged 49 years)**

Mark was a Wicking Community Participant who was prioritised on the waiting list to be next to move into The Wicking Household. He had an army of workers and services supporting him. Unfortunately all were fragmented and caught up in bureaucratic red tape making the process of change painfully slow.

Mark had lived a traumatic life filled with abuse, addiction and violence; however, upon meeting him he appeared to be a quiet, polite and solitary man, but was by no means a saint. He had perpetrated many an ill deed in his time. On paper Mark was the type of man you would not want to meet in a dark alley but in person Mark could be best described as "a broken man".



After much negotiation, planning and coordination, the path was finally made clear for Mark to move into The Wicking home the week after Easter. Mark had visited The Wicking residence on a couple of occasions, shared a BBQ with the residents and was looking forward to the prospect of moving in. The final external approval for the move was received late on Good Friday Eve. No one could contact Mark to tell him the good news. He was found dead under a railway bridge surrounded by alcohol bottles on Easter Monday. He was 48 years old.

Mark's story serves to remind us of the fine line that people living with an ARBI walk between life and death and inspires us to persevere at times when it appears that all avenues forward are being blocked by prejudice, naivety or bureaucratic red tape. People like Mark are unfortunately still falling through the cracks.

## 5.4 Measurement Outcomes

71

### 5.4.1 Analysis

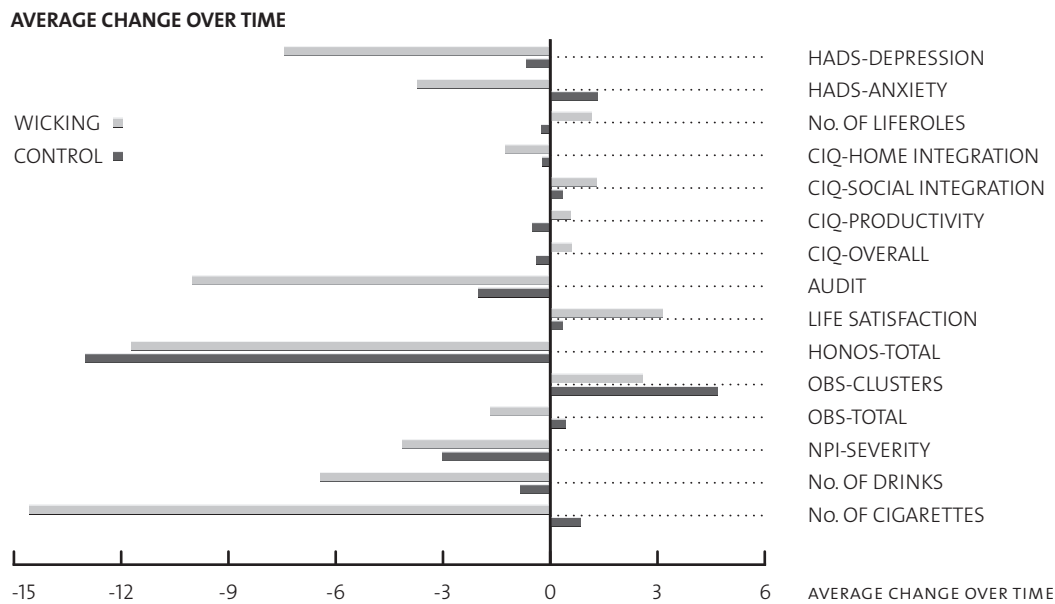
Four data-sets were established from the Wicking Project Trial outcome data. They were: 1. Outcomes of clinically validated measures; 2. Behaviour frequency observations; 3. Clinician-rated change in neuropsychological status; and 4. Frequency data for economic modelling. The findings of the analyses will be discussed below.

Clinically validated measures and frequency data were collected over eighteen months for all Wicking Project participants. The graphical representation of these findings is shown in Figure 15. The data-set represented scores collected from all 14 participants at two standardised time points during the trial. Time 1 represented the pre-trial test scores; Time 2 represented the test scores taken immediately prior to exiting the household for the Wicking Model Group and at the nine month time point for the Community Control Group. The third time interval occurring at the end of the eighteen month trial (Time 3) was not included in this analysis as this variable for the Wicking Model Participant group was not representative of an episode of consistent duration or homogeneous interventions, particularly for those who had left the Model within the first half of the Trial's implementation.

The Wicking Project data was initially examined using a series of multivariate tests. A series of Kolmogorov-Smirnov tests were conducted to examine if data were normally distributed. As all variables were found to be normally distributed, parametric statistics were conducted to examine group differences between residents of the Wicking Model Participants and Community Control Participants.

Clinically validated measures were analysed using a mixed model analysis of variance (ANOVA), with time point as the repeated measures factor and group (i.e., Wicking Model or Community Control Participant) as the between subject factor. Multivariate tests revealed significant time by group interactions for five variables; anxiety, depression, productivity, problematic drinking as determined by the AUDIT and the number of alcoholic drinks consumed. Further analyses of variance were conducted to examine the nature of the significant interactions, which indicated that significant changes occurred within the Wicking Model Participant Group over the 18-month Wicking Project Trial.

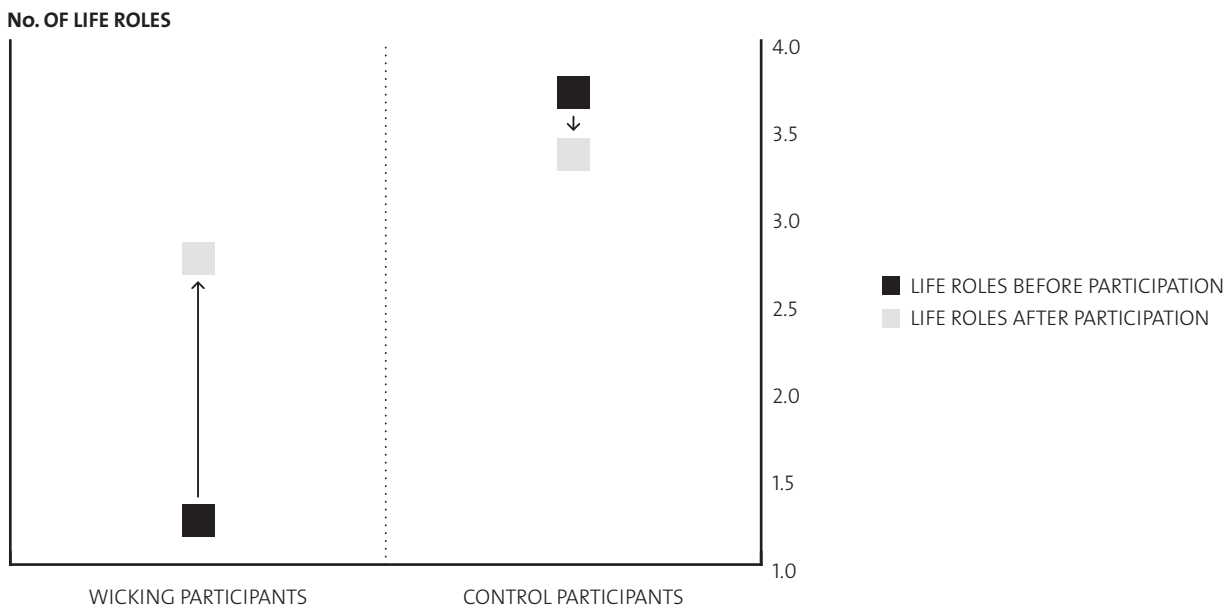
**Figure 15** The Average Change in Outcome Scores for Clinically Validated Measures



**5.4.2 Life Roles**

The primary outcome measure for this study was life role participation as measured by the Life Role Questionnaire. A modified version of the Role Checklist, detailing a list of 10 common life roles (student, worker, volunteer, caregiver, home maintainer, friend, family member, religious participant, hobbyist, participant in organisations and ‘other’). Data were only gathered from Part 1 to obtain the number of valued life roles. Total scores ranged from zero 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<sup>39</sup>. 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>.

Among Wicking Project Participants the total average number of life roles at the outset of the trial was 2.3, with the most commonly listed role being that of a friend or family member; however the most commonly cited friends 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. Figure 16 displays average life role participation scores in greater detail. It demonstrates that on average, the number of life roles among Wicking Model Participants increased by approximately 1.5 roles from 1.25 to 2.75 roles. The Community Control Group did not demonstrate any such increase although it was noted that this group did identify with a greater number of life roles at the outset of the trial. These notable, yet not statistically significant group differences were present in a number of other pre-trial assessment findings. The differences can be explained by the recruitment strategy whereby participants with the greatest need or those experiencing the greatest episode of life crisis were invited to participate in the Wicking Project Model (see 3.1.1 Participant Recruitment).

**Figure 16** Changes in the Number of Valued Life Roles Based on the Life Role Participation Survey

#### 5.4.3

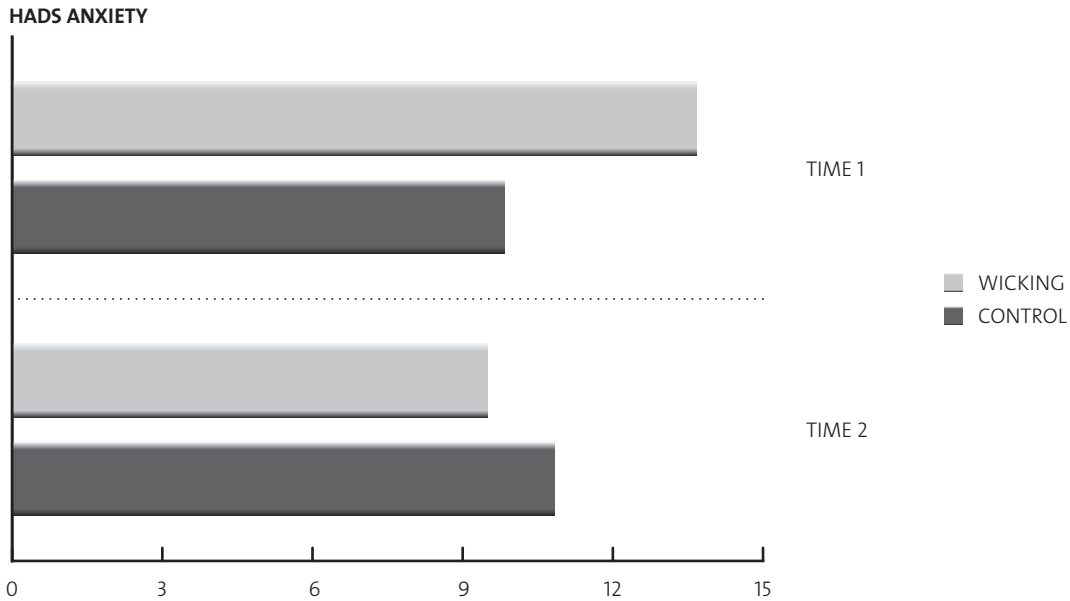
### Anxiety

A maximum score for both depression and anxiety as measured on the Hospital Anxiety and Depression Scale (HADS) is 21. Outcome scores on the HADS that rate below 7 are considered within the normal range. Scores that lie between 8 to 10 are indicative of a mild severity disorder. Scores between 11 and 14 are rated as moderate and 15 to 21 are rated as severe and a probable indicator of clinical pathology requiring further assessment. The majority of Wicking Project Participants fell within the latter two categories.

Increases in anxiety levels anticipated as a result of the move into the Wicking Household did not eventuate. This is most likely due to participants' past experience of multiple and frequent accommodation changes establishing resilience to the stresses of such transitions. Anxiety levels within the Wicking Model Participant Group were higher at pre-trial assessment which was most likely due to the anarchic chain of events necessitating their move from their pre-trial accommodation and referral to the project.

Average anxiety levels for the Wicking Model Participant Group dropped by 28% over the trial period whereas levels for the Community Control Participant Group remained relatively unchanged (12% increase). The significant decrease in stress level experienced by Wicking Model Participants during their participation in the trial is likely to be influenced by three key factors: the attainment of stable, secure housing; access to comprehensive health care; and being relieved of the stress created by the, at times all consuming quest to acquire alcohol.

**Figure 17** 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  $F=1.82, p=0.24$ )

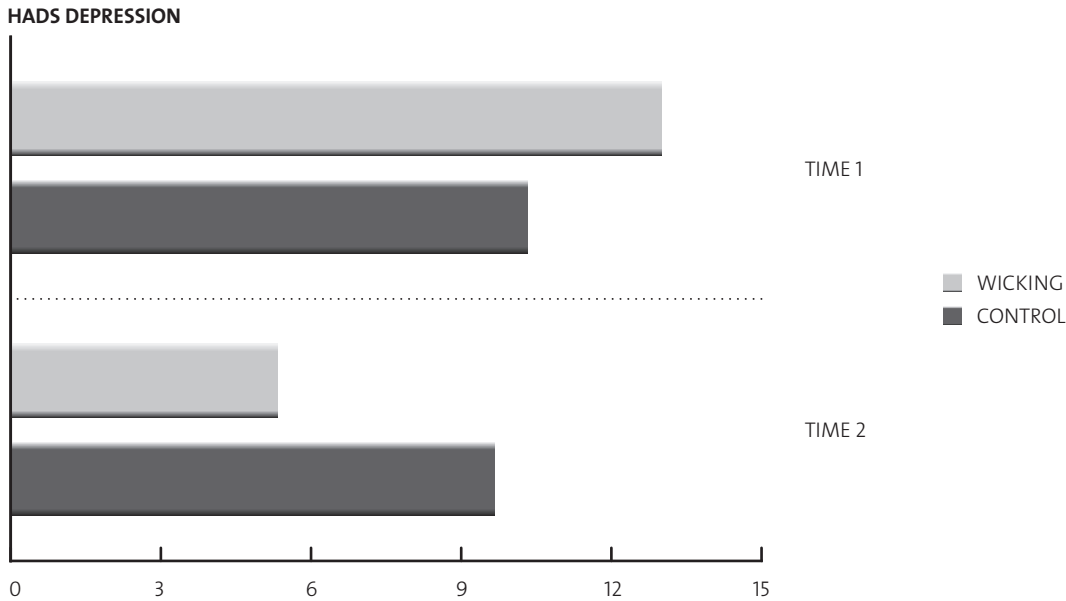


74

5.4.4  
**Depression**

There was a significant reduction in the level of depression experienced within the Wicking Model Participant Group over time as measured with the HADS. Average scores dropped 59% from a pre-trial classification indicating clinical pathology to well within the normal classification range. The Community Control Group scores remained relatively stable within the category identifying issues of concern (6% decrease). Group differences were thought to be principally influenced by three key factors experienced within the Wicking Participant Group: an increased sense of self-worth and usefulness (as indicated by the increased number of valued life roles – Figure 16); improved physical health; and increased opportunity for socialisation and participation in recreational pursuits.

**Figure 18** Hospital Anxiety and Depression Scale – 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  $F=0.10, p=0.77$ )

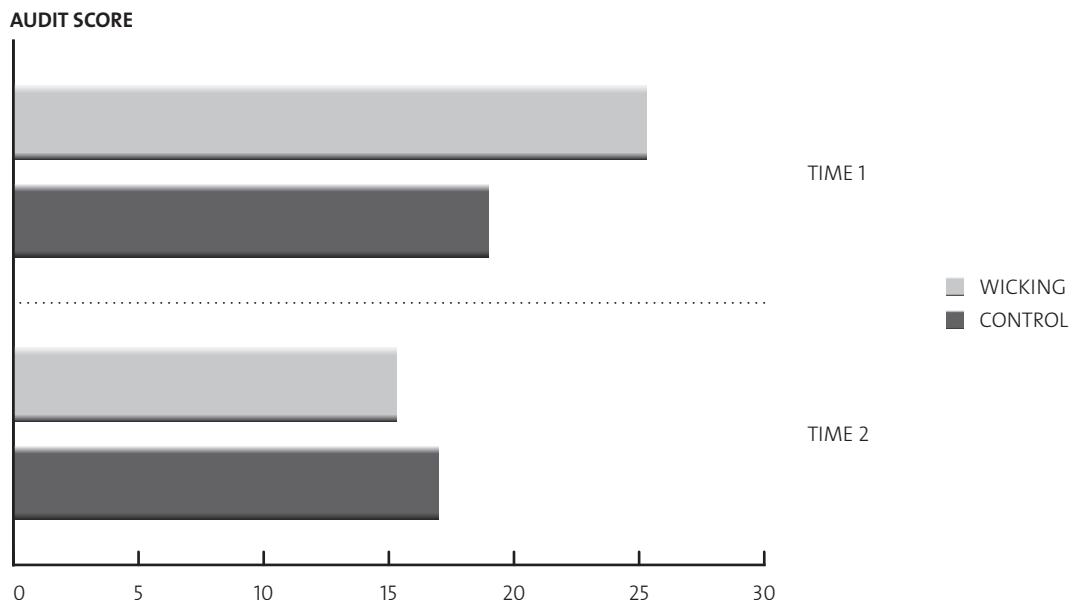


### 5.4.5 Alcohol Use Disorder

The Alcohol Use Disorders Identification Test (AUDIT) screening assessment tool is a questionnaire developed by the World Health Organisation to evaluate a person’s use of alcohol. Classification of drinking behaviour show 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>141</sup>. Not surprisingly, all Wicking Project Participants rated within the high risk category, especially the Wicking Model Participant Group for whom scores exceeded six score points above that of the Community Control Group. There was a small decrease of 10.5% (or 2 point scores) measured for the Community Control Group over time dropping within the high-risk range; however the Wicking Model Group experienced a significant drop of 40% (10 point scores) reduction in scores to place them well below that of the Community Control Group and within the lower range of the high-risk category.



**Figure 19** 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  $F=0.16$ ,  $p=0.60$ )



76

### 5.4.6 Alcohol Consumption

The average daily alcohol consumption measured for Wicking Project Participants was calculated by determining the number of standard drinks contained in the quantity of specific beverages consumed. Pre-trial estimates of drinking patterns of Wicking Project Participants show an average daily intake of six to seven standard drinks per day plus additional binges. Binges occurred at an average frequency of twice a week (ranging from once a week, to a month-long continuous binge occurring approximately once every four months). The volume of alcohol consumed during these binges was generally exceptionally large, for example: an entire slab of beer; a 2-litre cask of wine; and a 750ml bottle of spirits, all consumed within the one session. Previous research indicates that alcohol-related social problems are associated with the volume of alcohol consumed and the frequency of binge drinking<sup>142, 143</sup>.

The National Drug Strategy Household Survey (NDSHS) defines risk of harm in the short term (for example, motor vehicle accidents, falls etc.) 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. Risk of harm in the long term (for example, liver cirrhosis, ARBI etc) is defined as average weekly consumption of alcohol over the past 12 months that exceeds 29 standard drinks for males and 15 standard drinks for females<sup>144</sup>. A snapshot of alcohol consumption in Australia demonstrates (Table 5) that the Wicking Project Participants were by far a minority group within the population of ageing Australians<sup>145</sup>. All participants far exceeded drinking levels that placed them at significant risk of long-term harm.

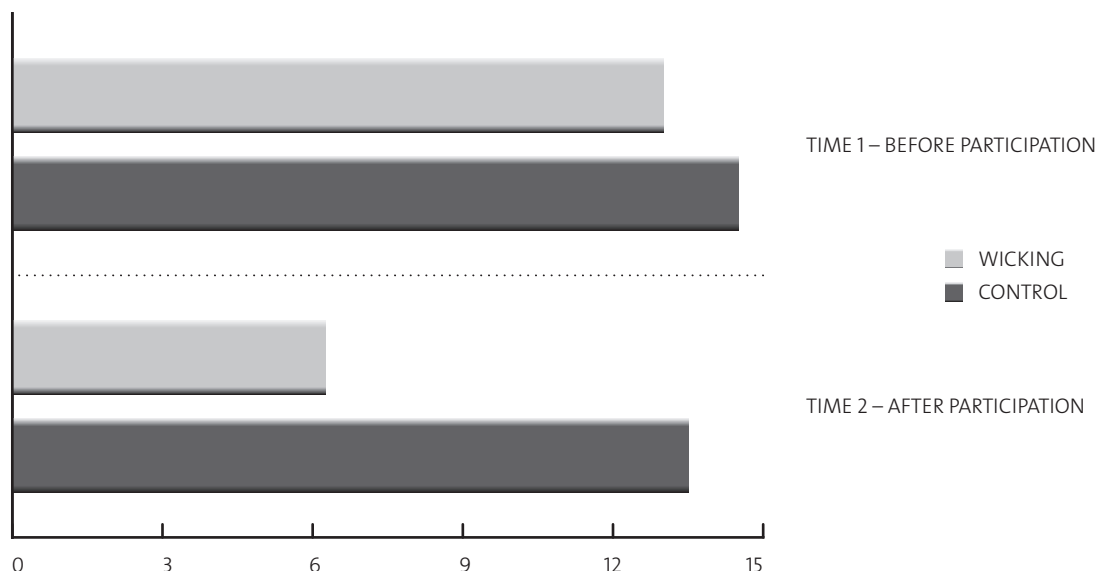
| Age group | Abstinent% | Low risk % | Risky % | High risk % |
|-----------|------------|------------|---------|-------------|
| 40-49     | 12.4       | 76.8       | 7.7     | 3.1         |
| 50-59     | 14.0       | 75.6       | 6.5     | 3.9         |
| 60+       | 24.7       | 68.9       | 4.8     | 1.6         |

**Table 5** Percentage of Older Australians at Various Levels of Risk of Long-term Harm Through the Consumption of Alcohol 2007

The Wicking Model Participant Group experience of a significant (40%) reduction in drinking levels which can, for the most be attributed to an effectively administered controlled drinking program; however, other factors such as improved health, a reduction in the levels of depression and anxiety and an enhanced role in community participation were also thought to have contributed.

**Figure 20** 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  $F=14.26, p<0.01$ , Control group by time  $F=1.24, p=0.32$ ).

**AVERAGE No. DRINKS/DAY**



**5.4.7**

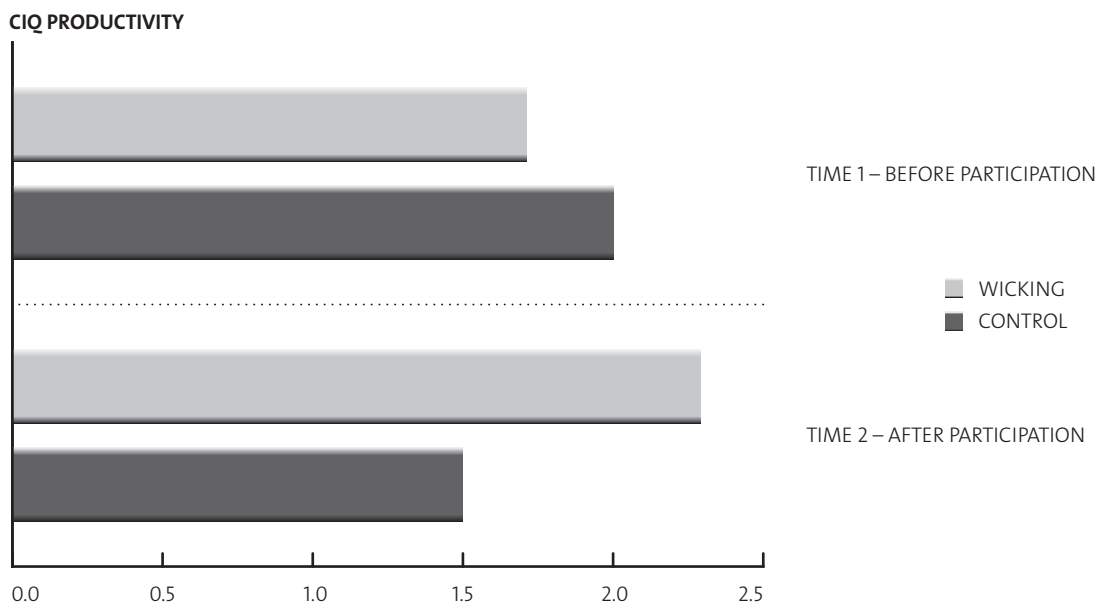
**Productivity**

A most important objective in a psychosocial program such as that provided by the Wicking Model is to maximise the participant’s level of reintegration into the community and return to productive activity. However, the cognitive, emotional, psychosocial and physical impairments associated with ARBI can limit an individual’s ability to return to productive activity, whether it is recreation, shopping, housework, or other endeavors. Individuals particularly from impoverished backgrounds often face difficulty in returning to productivity and normalcy.

In the Wicking Project there were significant group changes over time characterised by a modest increase in the levels of productivity demonstrated within the Wicking Participant group. This increase was achieved through the provision of interventions to support individual’s return to productivity, including compensatory strategies, role modelling, retraining and coaching. One of the key influences to the success 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 providing routine and structure in which the participant's skills and presence were valued and their limitations were accommodated.

**Figure 21** The Community Integration Questionnaire (CIQ) Productivity Subscale (Main effect – group  $F=0.51, p=0.50$ . Main effect – time  $F=0.03, p=0.88$ , Interaction effect  $F=5.66, p=0.037$ . Main effect – Wicking group by time  $F=3.69, p=0.10$ , Control group by time  $F=2.14, p=0.20$ )



78

### 5.4.8 Cigarette Consumption

Overall, the Australian population (aged 14 years+) smokes an average of 97 cigarettes per week. These figures, however are distorted by higher smoking levels in older age groups, for example it is known that smokers aged between 50–59 years smoke an average of 125 cigarettes per week. This trend applies to males and females (Table 6)<sup>146</sup>. Based on these figures the number of cigarettes smoked per day by the Wicking Model Participants almost doubled the national average prior to their commencement in the trial and then decreased to within close to normal range at completion of the trial. By contrast, average cigarette consumption levels for the Community Control Participant Group increased slightly over this period while still remaining within range of the national average.

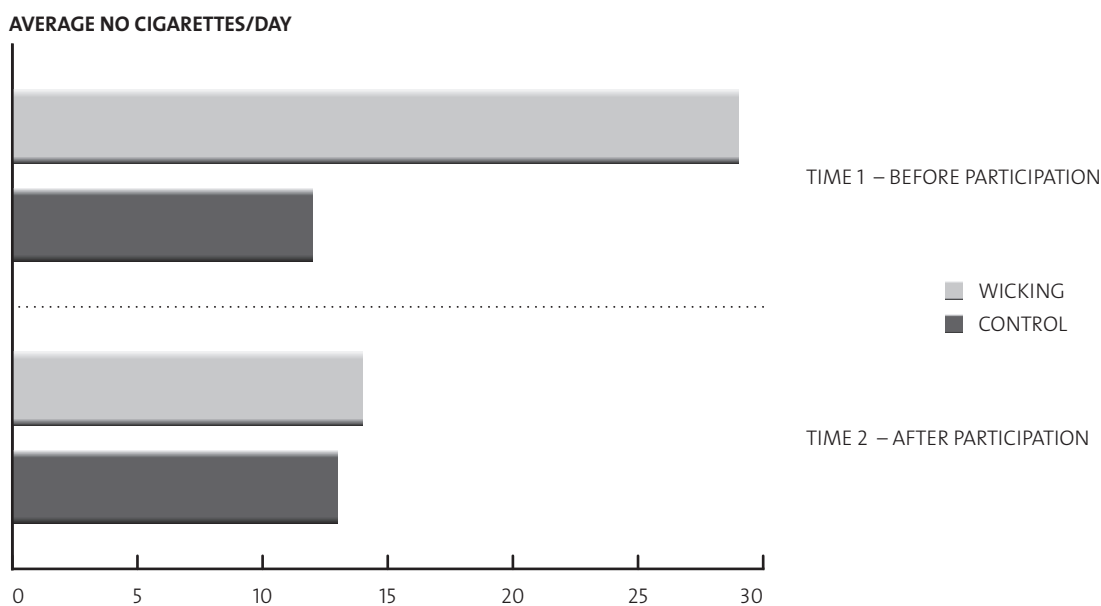
| Age group | Males | Females | Persons |
|-----------|-------|---------|---------|
| 50–59     | 135.9 | 110.2   | 124.9   |
| 60+       | 106.0 | 101.6   | 103.9   |

**Table 6** Mean Number of Cigarettes Smoked per Week, by Age and Sex, Australia, 2007

Only one Wicking Project participant did not smoke. Research has shown that individuals who report more symptoms of anxiety and depression are highly represented amongst those who smoke tobacco and consume alcohol at harmful levels<sup>147</sup>. Even more noticeable than with alcohol consumption, large group differences were present in the number of cigarettes consumed by Wicking Household Participants at the outset of the trial, smoking more than double the average

number of cigarettes as the Control Group. The reason for this can in some part be attributed to the previously discussed influence of greater levels personal hardship and life crisis at the time of recruitment. As with alcohol consumption, the large reduction in smoking levels experienced within the Wicking Model Participant Group (52% reduction) could be attributed to the controlled cigarette administration program as well as improved mental and physical health and enhanced participation in community and recreational activities.

**Figure 22** Number of Cigarettes Smoked per Day (Clinically Significant. Main effect – group  $F=1.58, p=0.24$ . Main effect – time,  $F=3.25, p=0.10$ , Interaction  $F=4.089, p=0.06$ )



#### 5.4.9

#### Satisfaction with Life

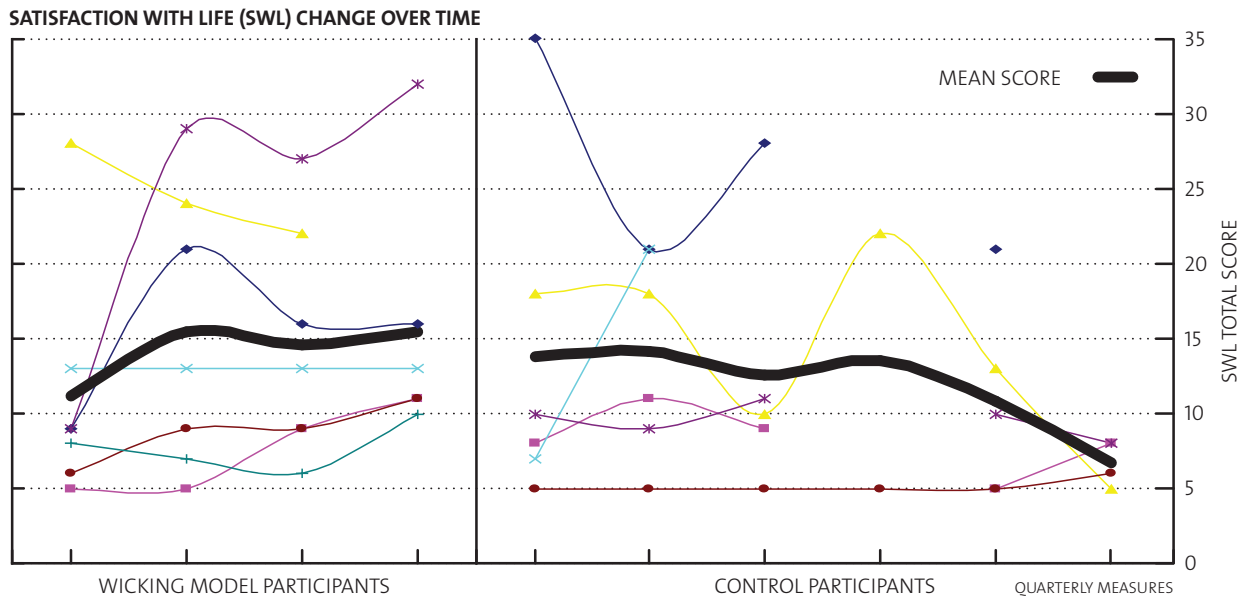
The Satisfaction with Life Scale (SWLS) measure was designed to assess an individual's global judgement of life satisfaction by allowing the respondent to weight the importance of life domains in accordance with his or her own values. Higher scores indicate greater levels of life satisfaction with a maximum score of 35. An average SWLS score within a normal aged population is approximately 26<sup>84</sup>.

The Wicking participant findings (Figure 23) show a lower than average satisfaction with life, with only three participants ever achieving scores that briefly exceed this value. No significant differences between groups was found ( $F=0.21, p=0.67$ ).

Despite the large degree of variability in responses provided by project participants, there was a general upward trend for Wicking Participants (as shown by the solid line in Figure 23) compared with the downward trend for the Control Participants. Life satisfaction within the Wicking Model Participant Group increased by 25% (4 score points) over the trial period whereas those of the Community Control Participant Group dropped by 57% (8 score points).

Please note that this graphical representation (and Figures 23 to 26) depict standardised assessment time points (quarterly) for the Wicking Model Participants over a twelve month timeframe which encompasses the period of Wicking Project Trial participation, whereas; the Community Control Participant data continues over an eighteen month period of project participation.

**Figure 23** Changes in Life Satisfaction Over Time for The Wicking Model Participants Compared with Community Control Participants



80

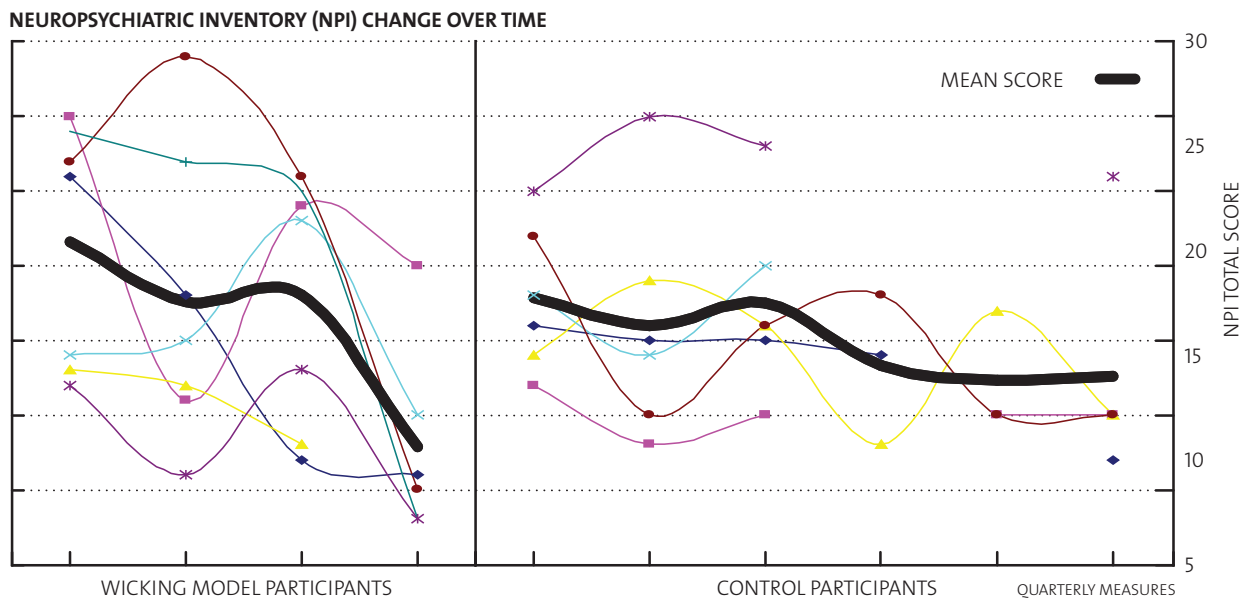
**5.4.10 Neuropsychiatric Behaviour**

The Neuropsychiatric Inventory Questionnaire (NPI) assesses non-cognitive psychiatric features and behavioural disturbance (elation/euphoria; apathy/indifference; disinhibition; irritability/lability; motor disturbance; nighttime behaviours; appetite/eating). Higher scores indicate greater severity in neuropsychiatric behavioural disturbances. Approximately ninety percent of regular aged care clients rate NPI scores of 15 or less<sup>148</sup>.

No significant differences between groups ( $F=1.91, p=0.21$ ) were shown, however there was an overall significant decline in scores over time for both groups ( $F=7.58, p=0.03$ ). As seen in Figure 24, Wicking Model Participants’ average score prior to the commencement of the trial was 22, rating in the most severe classification range; however, by the end of the trial, their average score dropped some 66% (14.5 point scores) placing this group within the mild classification range. The Community Control Participant Group decreased only 29% (5 point scores) over time remaining within the moderately severe classification range.



**Figure 24** Changes in Neuropsychiatric Behaviour Over Time for The Wicking Model Participants Compared with Community Control Participants



#### 5.4.11

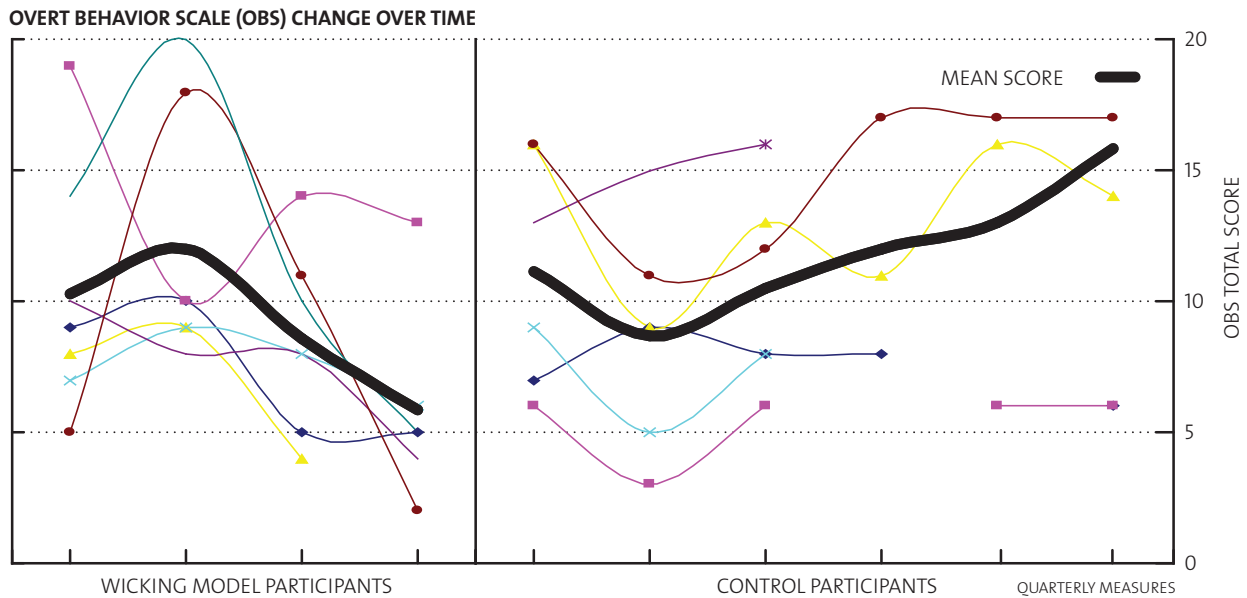
### Overt Behaviour

The Overt Behaviour Scale (OBS) was used to measure changes in challenging behaviour<sup>91</sup>. 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 disturbance. The OBS was selected over other measures of challenging behaviour because of its suitability for use in a community setting and for a range of disability groups, and it covers a broad spectrum of challenging behaviours<sup>149</sup>.

No significant differences between groups ( $F=0.01$ ,  $p=0.98$ ) was found, however there was an overall significant decline in scores over time for both groups ( $F=13.36$ ,  $p<0.01$ ). There was a strong trend ( $F=4.54$ ,  $P=0.07$ ) for greater decline in NPI scores for the Wicking participants over the period of the intervention.

Group differences over time are shown in Figure 25. This figure clearly shows that behavioural disturbances among Wicking Model Participants reduced by approximately 48% after an initial rise at the three month mark (discussed later in Chapter 5.4.15), whereas the Community Control Participant Group experienced a steady increase in these behaviours after an initial reduction.

**Figure 25** Changes in Overt Behaviour Over Time for The Wicking Model Participants Compared with Community Control Participants



#### 5.4.12

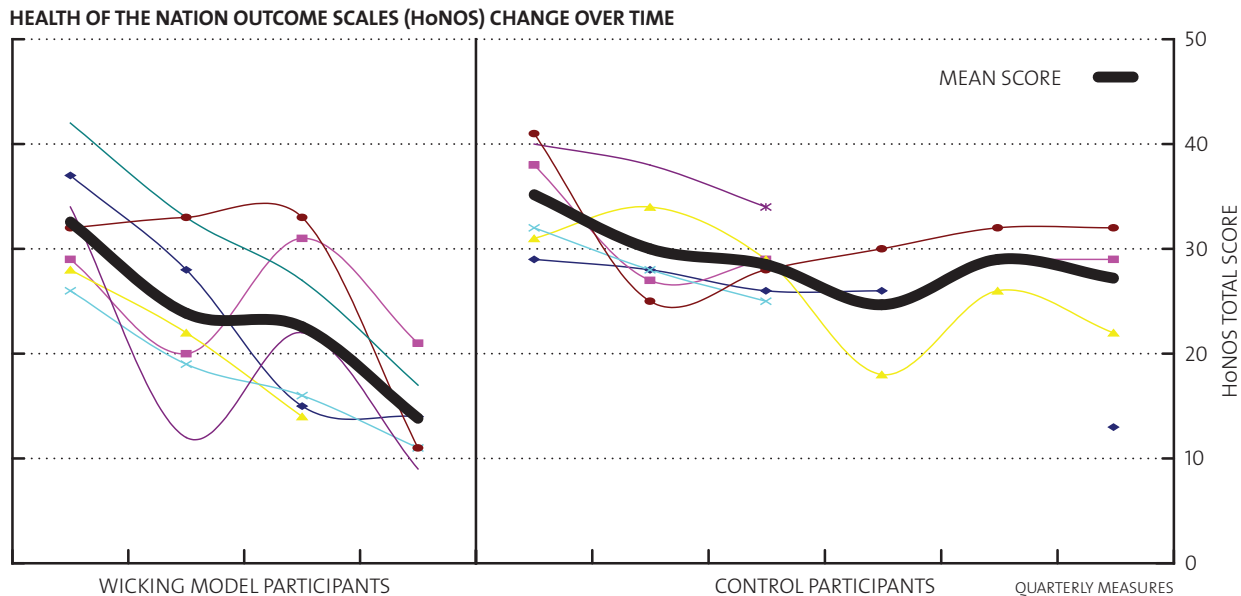
### Health of the Nation Outcome Scales

Health of the Nation Outcome Scales (HoNOS) scores are designed to 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 severe mental illness. The HoNOS 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>50</sup>. These findings indicate that with an average score of 34.5, The Wicking Participant population did indeed present with an extremely high level of psychosocial problems.

A mixed model ANOVA with time as a repeated measures factor and group as a between subjects factor showed a significant interaction effect ( $F=5.44, p=0.05$ ). Further analysis revealed that the HoNOS scores for the Wicking participants decreased significantly over the 12 month period of intervention ( $F=50.14, p<0.01$ ), compared with control participants who did not show a significant change in HoNOS scores over the same time frame ( $F=8.68, p=0.09$ ).

Throughout their participation in the trial the Wicking Model Participants improved their functioning on nearly every HoNOS scale. Participants showed significant levels of improvement on the scales measuring problems with cognition, depressed moods, living conditions, and occupations and activities. Figure 26 displays group changes in average HoNOS total scores over time. The Wicking Model Participants experienced a 57% reduction in these values while the Community Control Group values decreased by 21%.

**Figure 26** Changes in Health of the Nation Outcome Scales over Time for The Wicking Model Participants Compared with Community Control Participants



#### 5.4.13

### Physical Health

As a permanent resident of an aged care facility, Wicking Model Participants all received comprehensive medical assessments. These assessments provided a window of opportunity for participants to gain access to medical and psychosocial tests and interventions that are not readily available or accessible in the community. The assessments reviewed all aspects of the participant's health and physical and psychological functioning including:

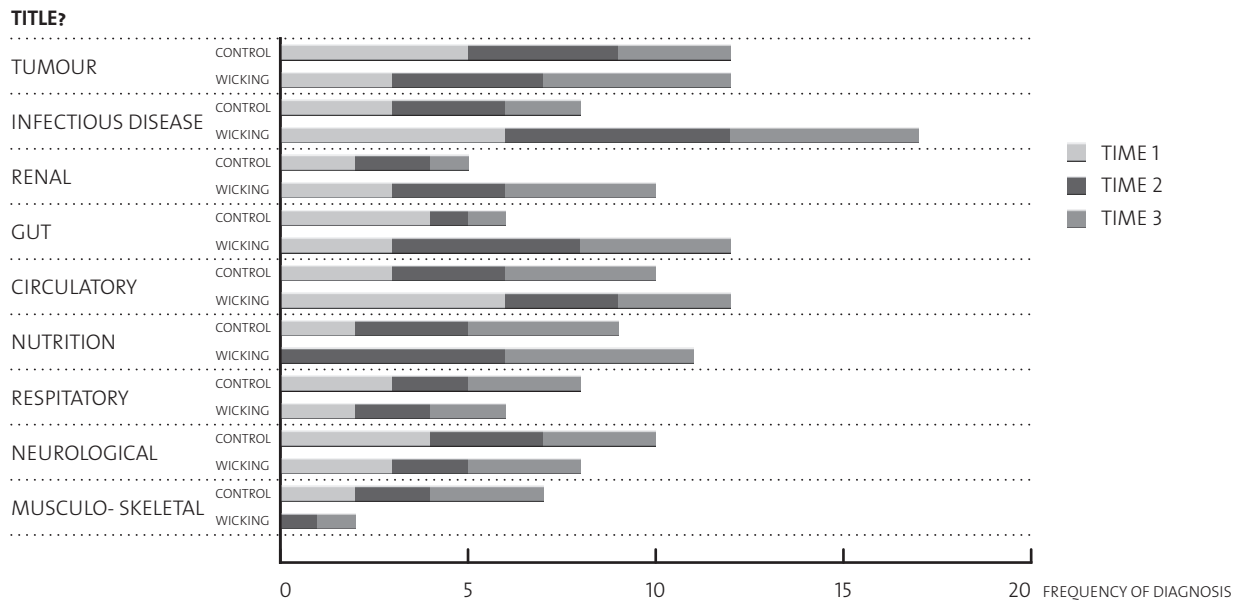
- Activities of daily living;
- Psychological function, including cognition and mood;
- Oral health, nutrition status and dietary needs;
- Skin integrity;
- Hearing and vision;
- Smoking and alcohol use;
- Foot care;
- Sleep; and
- Incidents of falls.

At the commencement of the trial the physical health profile of Wicking participants was representative of an older homeless population in Melbourne<sup>55</sup> (see Table 1). In fact the Wicking Model participant group experienced on average a greater number of health complaints at the outset.

In addition to positive changes in psychological health, the general health of The Wicking Model Participants improved significantly and then was successfully maintained with fewer physical health problems than the Community Control Participants for the duration of the trial. Figure 27 demonstrates that neurological and gastro-intestinal health problems predominated in the Community Control Participant group and musculo-skeletal and respiratory disorders were shown to increase over the duration of the trial.

Within the Wicking Model Participant group nutritional and musculo-skeletal health issues predominated at the outset of the trial and then reduced over the duration of the trial leaving circulatory and gastro-intestinal ill-health as the most frequent disorders. Overall the Wicking Model participants experienced 25% less health complaints compared with the Community Control Participants.

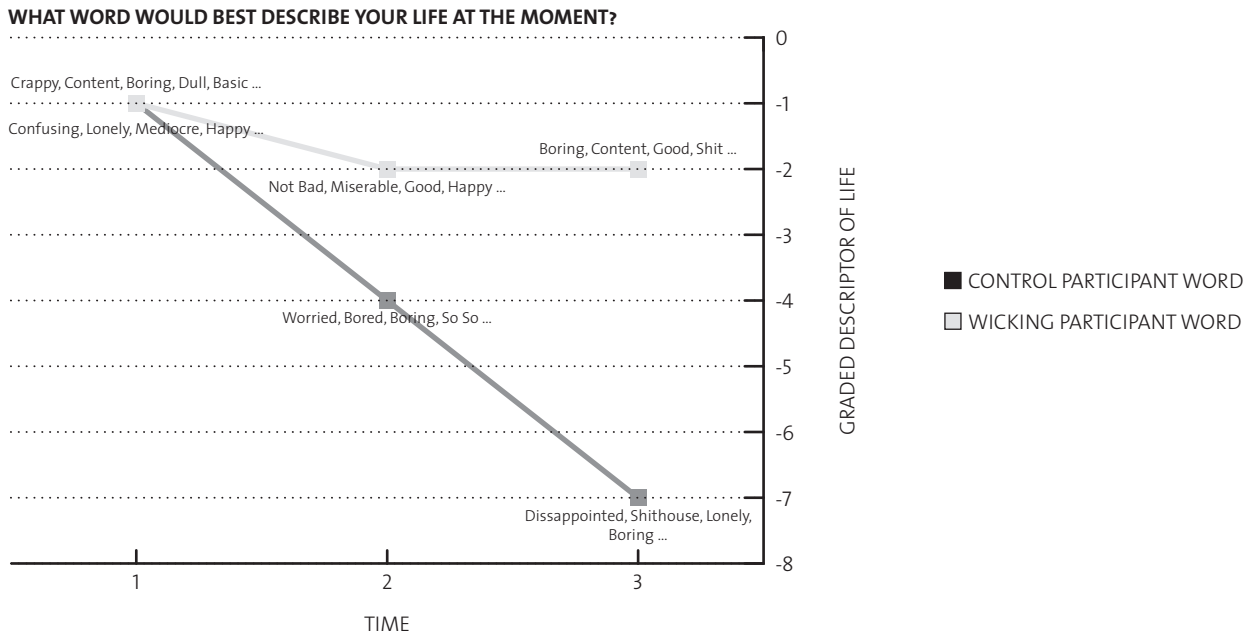
**Figure 27** Changes in General Health Conditions Over Time for The Wicking Model and Community Control Participants (Time 1: Outset, Time 2: 9 months, Time 3: 18 months)



**5.4.14 Subjective Wellbeing**

The outcome of several, if not all, measures in The Wicking Project evaluation inventory could be indicative of change in Participants’ subjective wellbeing. Positive change measured in a person’s mental health, physical health, behavioural disturbances, drinking behaviour or level of social integration could all equate with improved wellbeing. Based on these measures reported above, The Wicking Model Participant Group’s state of wellbeing was seen to improve over the trial period, whereas they remained unchanged or were seen to deteriorate for Community Participants. These findings were also reflected in another 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 3-monthly intervals throughout the trial. A graded representation of the responses is shown in Figure 28.

**Figure 28** Graded Subjective Descriptors of Life Quality Over Time (Time 1: Outset, Time 2: 9 months, Time 3: 18 months)



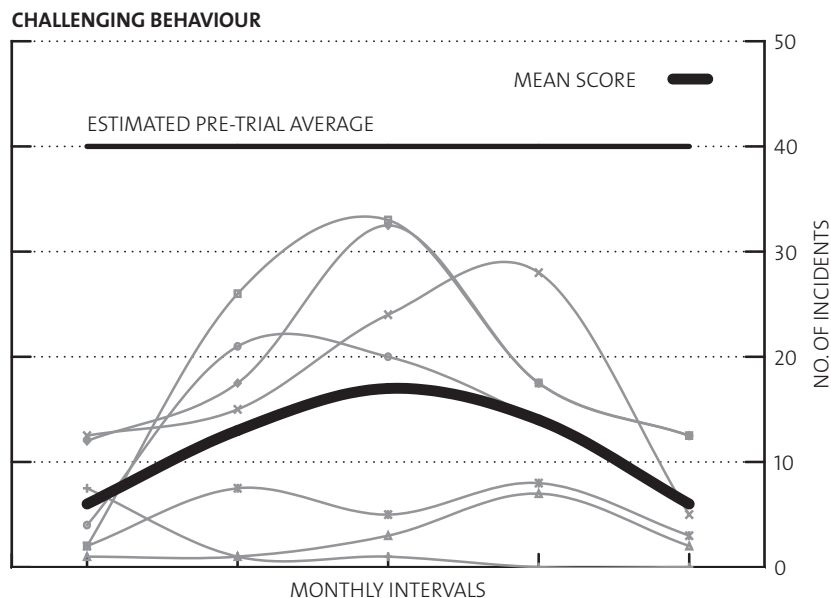
**5.4.15 Behavioural Changes over Time**

Behaviour frequency data was collected for the seven Wicking Model Participants. The data-set represented scores collected at monthly intervals throughout the participant’s term of residency. Consistency of data was maintained for the first 5 months of residency for all participants and therefore these time points were selected for analysis. Kolmogorov-Smirnov tests determined that all frequency scores were found to be normally distributed and were therefore analysed using a Repeated Measures analysis of variance (ANOVA) following a general linear design. Analysis revealed significant Huynh-Feldt time interactions for three variables being: Observed intoxications, Verbal aggression and Total challenging behaviours. Posthoc T-test analyses revealed that these significant interactions existed for the Wicking Model Participant Group.

A characteristic hill-shaped curve existed for all behaviours of concern indicating a strong pattern of behavioural change. This change has characterised by low frequency of behaviours immediately after moving into the new environment “cautious phase” then an incremental rise in behaviours over the first two months “testing the waters phase”, peaking at the third month “chaotic phase”. An incremental decline in behaviours then followed over the next two months as behaviour modification strategies, familiarisation and an increased sense of safety began to take effect. By about the fifth month, the frequency of behaviours then settled to approximately the same level as at the commencement of the trial. In successive months the behaviours then attenuated around the 5-month level for those who remained in the home for longer periods of time.



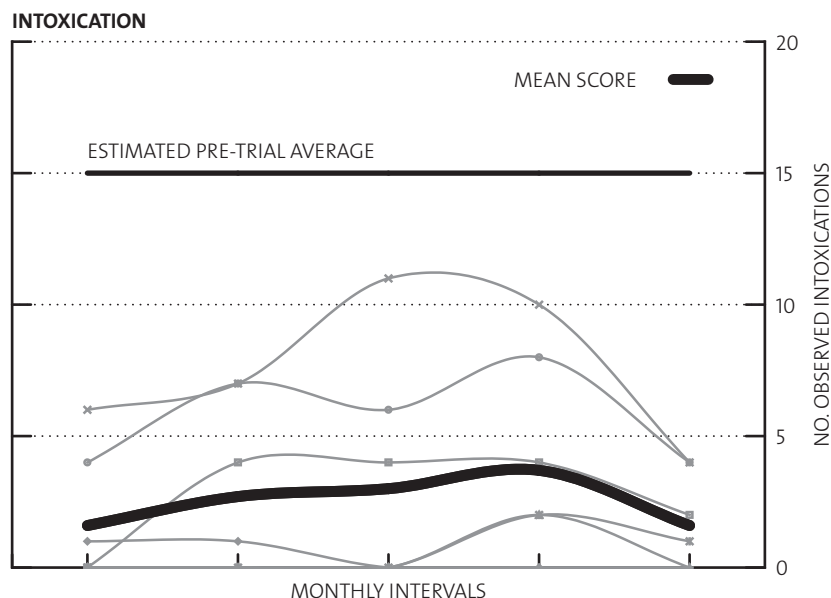
**Figure 29** Frequency of Incidents of Challenging Behaviour Overall Among Wicking Model Participants Over Time (Main Effect  $F=4.820, p=0.008$ . Further analyses showed significant differences between Time 4 & Time 5  $F=8.57, p=0.026$ )



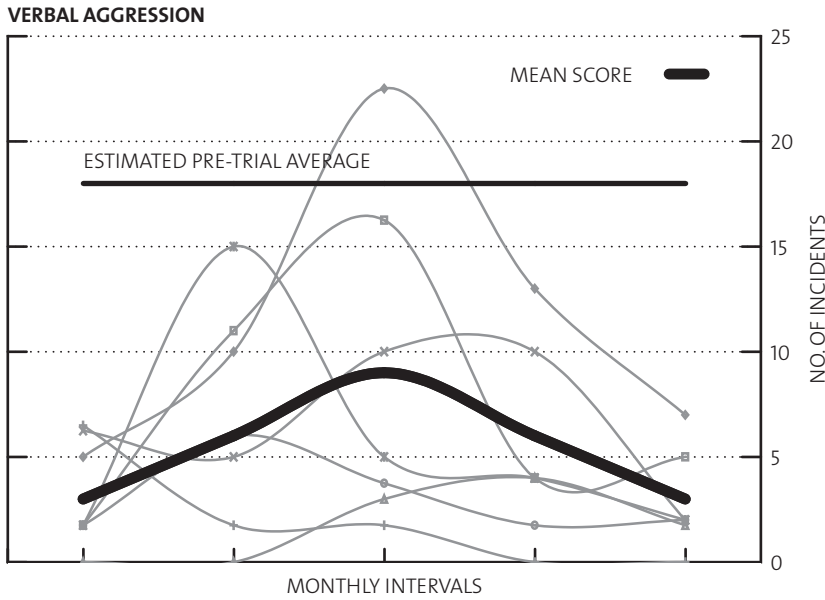
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This finding educes a significant point of learning for the introduction of new residents exhibiting challenging behaviours into new residential care environments whereby staff can anticipate and plan for a peak in the frequency of challenging behaviour at approximately the 3 month period of residency.

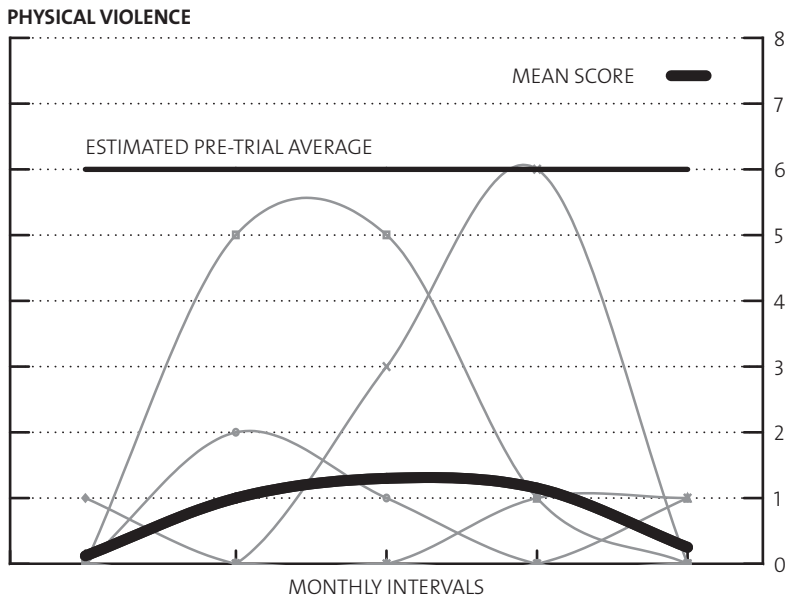
**Figure 30** Frequency of Observed Intoxications Among Wicking Model Participants Over Time (Main Effect  $F=3.499, p=0.037$ . Further analyses showed significant differences between Time4 & Time5  $F=3.81, p=0.043$ )



**Figure 31** Frequency of Incidents of Verbal Aggression Among Wicking Model Participants Over Time ( $F=3.058$   $p=0.046$ ). Further analyses showed significant differences between Time3 & Time5 ( $F=8.83$ ,  $p=0.037$ ).



**Figure 32** Frequency of Physical Violence Among Wicking Model Participants Over Time ( $F=0.844$ ,  $p=0.49$ )



**5.4.16 Relationship 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 reported below. Detailed correlation outcomes are shown in Appendix D, however the following interesting co-relationships are discussed further.

The Wicking 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. Although one-way causal relationships involved in such statistical associations are hard to substantiate, this finding is in line with well established research that show that high levels of depressive and anxiety symptoms reported by adult smokers<sup>151, 152, 153</sup> and drinkers<sup>152, 154</sup> indicate a substantial relationship between alcohol, tobacco use and mental ill-health.

The results 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. Life satisfaction was shown to decrease the younger a participant was when they first started drinking. Lower satisfaction levels were also recorded for participants experiencing higher levels of problematic drinking. These findings reflect those of a large American study that found significant differences among individuals with different drinking patterns with respect to life satisfaction<sup>155</sup>.

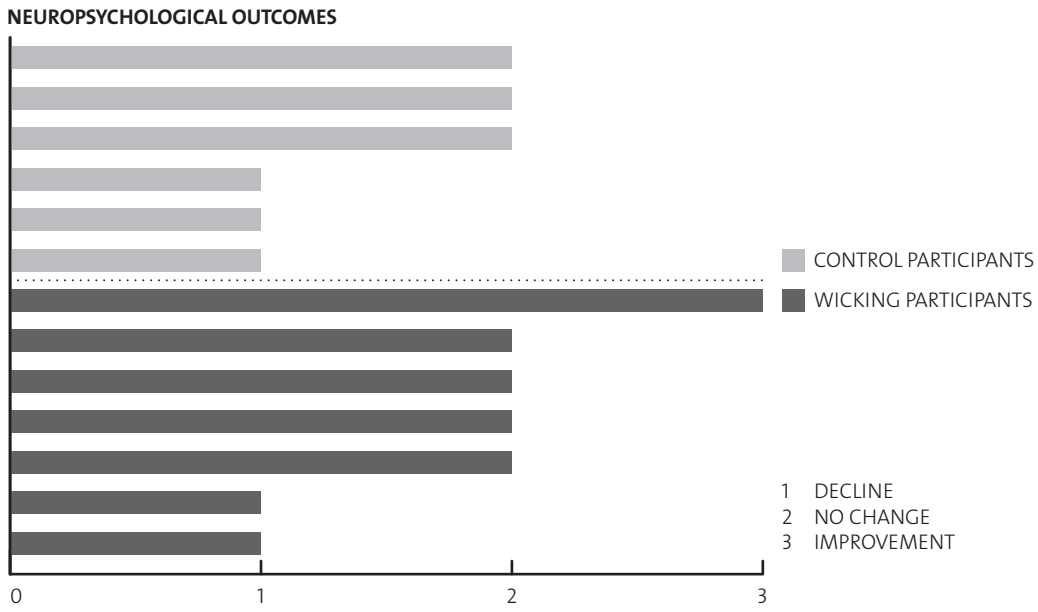
Increased levels of home integration (identifying with oneself as being an integral member of a household) were significantly associated with a reduction in smoking. This finding could be attributed to a reduction in the level of boredom through the engagement of purposeful activity, but could equally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

#### 5.4.17

### Neuropsychological Outcomes

All participants underwent two Neuropsychological Assessments, one at commencement and another at completion of the trial. Categorical classifications were made as to the amount of change measured in neuropsychological parameters between Time 1 at the outset of the trial and Time 2 at the conclusion of the trial (18 months later). A number of factors had to be taken into consideration in the final determination of change. They included; varying levels of alcohol intoxication at the time of assessments and inconsistent or missing data due to varying levels of attentiveness or cooperation. The determinations of change were made by the independent ratings of two neuropsychologists. These neuropsychologists were also responsible for conducting the neuropsychological assessments. The three categories of change were identified; 'No Change', 'Improved', and 'Declined'. The data was analysed using Chi-Square Tests. No statistically significant differences were found; however Figure 33 demonstrates that Wicking Model Participants did perform marginally better overall as indicated by less participants showing deterioration and one participant demonstrating mild cognitive improvement.

**Figure 33** Clinician Rated Cognitive Change Over the 18 months for Wicking Project Participants



## 6 Discussion

Even with the highly individualised program offered by The Wicking Model, there were still individuals for whom it was not suited. Despite a fundamental component of the model being the empowering of participants to exercise their freedom of choice, some regulatory practices were unavoidable in the conduct of service delivery. Some of these practices were driven by the need to comply with government agency regulations, standards and accreditation requirements, but for the most they were driven by the need to establish and maintain high levels of enquiry and vigilance to effectively administer medical and behaviour management care plans and to ensure the safety of participants and others. Intensive support therefore came at the price of intense scrutiny.

For example, despite the absence of locked or key-coded doors restricting movement in and out of the home, participants were still required to inform staff of their movements as well as provide details as to the nature and duration of activities to be undertaken. This practice, undertaken in compliance with regulatory processes and duty of care, was understandably viewed by some participants as an invasion of privacy, particularly when they had entered the home directly from an unrestricted community-based lifestyle.

90

Because ARBI frequently impairs executive functioning, the essential cognitive component required to enable participants to rationalise the relationship between the personal choices made and the resultant spiralling decline in health and wellbeing, was impaired or absent. Therefore participants displaying a vehement dislike of rules and restrictions did not respond well to this model and the introduction of such measures did in fact trigger increasing behavioural disturbances.

Housing and support models often assume that older clients require a static level of support without consideration of the potential for transition into other, less intensive residential care environments in the future. 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.

For formerly homeless older adults, the risk to stability in health, behaviours and wellbeing associated with moving to a new residential care setting must be mediated by the establishing of links to ongoing and appropriate support prior to the move. Although the most formidable barrier to housing transition is the scarcity of affordable, appropriate accommodation and support options, other considerations must include the vulnerability introduced by the move itself. Transitions should therefore be trialled and barriers removed, ensuring that people could 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.

This project has elicited three key, yet interconnected, challenges to the effective delivery of appropriate support services to older people living with complex challenging care needs arising from long term alcohol abuse.

### 6.1 Social exclusion

The varied and pervasive forms of discrimination experienced by older adults limit their ability to secure accommodation, access appropriate services and to realise meaningful social integration. Classism, ageism and stigmatising labels are all critical barriers that must be overcome. Alcohol and drug abuse are heavily moralised issues often resulting in stigma and marginalisation. Service



staff may view alcohol and other drug use behaviour as a 'personal choice' long after the functional and structural changes of ARBI have occurred, rendering the person unable to regulate motivational impulses and stop alcohol consumption despite its harmful consequences.

Homelessness itself carries a stigma that affects access to, and the use of public and private services. Furthermore, services that are in the front line of response to homeless people may be staffed by people with little understanding of the needs of homelessness and are structured around the assumption that people intentionally become homeless or are seeking to deceive. A culture change is required by service providers to ensure that they promote values, attitudes and behaviour that deliver responsive and personalised services, and effectively prevent formerly homeless older adults from a cycle back into homelessness.

An older person displaying vulnerable, challenging and unpredictable behaviour, often as a result of a traumatic and abusive life history, may find themselves socially isolated and homeless. The effects of a homeless lifestyle combined with accelerated aging, chronic mental illnesses and the presence of an ARBI, can influence the ability of older people to recover and to improve health and wellbeing.

The combination of challenging and confronting behaviours and continued drinking, usually present as an unattractive and unwanted source of referral to service providers. The absence of family carers or close friends shift the onus of advocacy to service staff who often lack the time and empathy required to navigate the complex service system with the aim to attain access to appropriate support. The special needs and general lifestyle characteristics of people that meet the Wicking Participant profile are key elements that contribute to the level of disadvantage experienced when it comes to accessing the most appropriate aged care services.

With a high percentage of people presenting with long and established histories of drinking, smoking, gambling, crime and alcohol related brain injury, 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, in order for support services to deliver care that is appropriate and effective, they must possess knowledge of the underlying and often multifactorial cause of the behaviour, and be skilled in the delivery of effective responses taking into consideration the limited cognitive capacity of individuals living its effects.

The finding of definitive solutions to these problems were beyond the scope of this project; however, the following suggestions are drawn from the Wicking Project experience. A worthwhile public health policy goal would be to eradicate or minimise stigma-related obstacles wherever possible. This can be achieved through the building of fundamental knowledge on the effects of homelessness; alcohol related brain injury and complex care needs within the service industry. Such initiatives could include:

- National institutes, health care organisations, policy making bodies, and criminal justice systems ensuring that they incorporate this information in all staff induction and continuing education programs. Staff should be supported to expand and maintain their level of expertise in relation to the needs of specific client groups;
- This information should be entrenched in the syllabus of all health and social science education programs extending from vocational training to undergraduate and post-graduate university courses;
- Older people who are homeless are forced to endure the humiliation and indignity of having to retell their life story time and time again. Every time they go to a new service, or even sometimes when they return to a service, they are asked to provide this information. This is a very wearying

and frustrating process which could be avoided through a centralised record of client information that is accessible by key service personnel. Understandably, issues pertaining to privacy and consent must be addressed; however, a solution to this unnecessary burden must be found.

- Older adults who have experienced homelessness have a tremendous amount of knowledge which could be integrated into programming, materials and policies affecting the homeless community. The empowerment of individuals to share their life stories using various forms of media or peer support could provide a powerful tool to the benefit of both the older person living with an ARBI and the people who learn from them.

## 6.2 Service Integration

When Wicking Project Participants were homeless or at risk thereof, they faced a daily challenge of negotiating fragmented, inaccessible service systems, a process exacerbated by the lack of professional specialised services. There are several observations made through the implementation of The Wicking Project that highlighted some key contributors to this service system failure.

The inability of participants to gain access to appropriate support services based on highly exclusive eligibility criteria occurred all too often in the Wicking experience. For example, it had proven difficult to argue the case for premature ageing among homeless people, which is determined by Wintringham to apply to people aged fifty years and older. Recognition by the Australian Government of older homeless people as having 'special support needs' will hopefully contribute to improving accessibility. However, the effectiveness of this initiative will only be realised when staff awareness and administrative processes are oriented toward the accurate identification of people with this priority need and expediting an appropriate service delivery response.

Some other initiatives to support better service integration could include:

### 6.2.1 Research

- The use of assessment tools, such as that developed by Common Ground Services in the United States, which are used to determine the vulnerability of homeless people and prioritise service needs<sup>56</sup>. The Common Ground Vulnerability Index enables services to identify the most vulnerable homeless people living in their community and develop an individualised, coordinated response specific to that person's needs.
- Improved clarity and understanding as to the process, roles and expectations of service providers can be achieved through projects such as that currently being conducted through Griffiths University, Queensland. This project aims to analyse the shortfalls and states of precariousness in human service delivery and social policy to people with impaired decision-making capacity who are chronically homeless and who continue to experience marginalised lives and gross social exclusion. The Wicking Project research team are contributing to this project through their participation in the reference group;
- A 4-year flagship project announced by the Victorian Government initiative titled 'A Better Place Victorian Homelessness 2020 Strategy' proposed to examine the need to coordinate and evaluate a range of support services to meet the needs of older people, including access to affordable housing, specialist health and mental health services, home assistance services and social and recreational programs. Although a subsequent change of government could potentially quash this strategy, initiatives such as these must continue in order to gain a better understanding as

to the service requirements of older people and to build a stronger evidence base as to which interventions are most effective in addressing the drivers of homelessness and continued alcohol abuse within this population.

### 6.2.2

#### Regulatory Processes

While many health and social care reforms in Australia have as their goal improvement in the efficiency, quality and safety of Australian health and social care, there is considerable frustration with the increasing amount of red tape created from different areas, seemingly unaware of each other and the effect this has on a person's ability to access appropriate care. Other considerations include:

- The social stigma attached to ARBI, resulting from its association with alcohol, mental health problems and dementia, needs to be addressed beyond the individual to institutional and societal levels. Future strategic development of information, advice and health promotion services will assist in addressing these issues;
- Effective regulation is essential to ensure services operate efficiently and fairly to protect consumers, services staff and the environment. However, the benefits of regulation must not be offset by an unduly high burden of compliance and implementation. For example, the lengthy and arduous process of applying for Individual Support Package funding.

93

### 6.2.3

#### Resource Allocation Processes

Service providers and service users alike are frustrated at not knowing the rationale or method of current resource allocation. There is an evident need for an assessment and resource allocation process that is applied consistently across all funded services. Variations in resource allocation practices currently exist across different agencies, regions and States. This could be assisted by:

- Fair and transparent resource allocation processes based on a broad understanding of the specific support needs of an individual, as well as the resources that are currently available and those being utilised/underutilised. Future arrangements would require greater connection between government and non-government agencies and open communication as to the level of service usage and capabilities within various sectors;
- Funding bodies must avoid preferential consideration of funding applications that use industry-specific language and terminology. The expectation that applications be completed using such language prejudices against lay or semi-expert applicants.

### 6.2.4

#### Recognition and Utilisation of Skills & Expertise

It should be recognised that many agencies in both the government and non-government sectors provide specialisation around various disabilities. Funding bodies should recognise the competence of agencies with established areas of expertise to accurately determine the specific nature of support requirements for their clients and the urgency with which these clients are in need of this support. Governments need to maintain positive partnerships with these organisations and encourage the sharing of information and resources to the mutual benefit of people with multiple and complex needs. For example, public hospital care and discharge planners not seeking consultation with the patient's residential care service provider.

## 6.2.5

**Specialist Services**

The most significant accessibility obstacles encountered in this project involved mental health and drug and alcohol services. The issues pertaining to mental health have been previously discussed in reference to dual diagnosis (Chapter 5.2.3). Other observations relate to accessibility to specialist support services in the event of prolonged episodes of alcohol-fuelled aggression and high-risk behaviours.

Situations in which prolonged episodes of acute intoxication lead to extreme levels of physical violence and significant risk of harm to the individual, members of the community, service staff or other service users, are generally very poorly managed within the current service system. Often these individuals are optimally supported in an environment that does not allow freedom of access to alcohol. In some situations this would require involuntary admission into a secure locked facility. In Victoria, The Drug and Alcohol Act of 1968 did not provide the authority for this to happen as, in most situations the person only became aggressive when intoxicated and was therefore not considered at constant risk of engaging in high-risk behaviours.

94

During the implementation of The Wicking Project Trial, The Drug and Alcohol Act (1968) was in force. A significant weakness of this act related particularly to people living with an ARBI and that it did not allow for the extreme level of risk presented by some of the behaviours exhibited and the frequency at which this could occur. Of particular concern was when alcohol-fuelled aggression was accompanied by an ARBI. As discussed previously, regulatory control which is usually mediated by the brain's frontal lobes is often compromised in this population resulting in a failure to curtail the urge to drink. This leads to situations for example, where individuals are immersed in prolonged and excessive drinking binges sometimes involving up to two casks of wine a day for periods lasting up to one month. If this person were housed together with frail, vulnerable people, the level of risk was further exacerbated.

**Addendum:** In 2010, the Severe Substance Dependence Treatment Act (SSDT Act) was introduced to repeal and replace the Alcoholics and Drug-dependent Persons Act. Implemented in April 2011, the purpose of the SSDT Act is to provide a last resort treatment option to a very small group of people affected by severe substance dependence. It provides for the detention and treatment of persons with severe substance dependence where this is necessary as a matter of urgency to save a person's life or prevent serious damage to a person's health. The detention and treatment is aimed at providing a critical intervention lasting up to 14 days that will assist to break the destructive cycle of drinking. This is achieved by providing access to medically-assisted withdrawal, to allow comprehensive medical assessment and commencement of appropriate treatment options and a coordinated service response leading to referral and ongoing service engagement. Although the full implication and ramifications of this Act are yet to be realised, careful administration and implementation could have a significant positive affect on the lives of a small number of people living with an ARBI and extremely challenging behaviour.

## 6.3

**Structural Factors**

The findings of The Wicking Project highlight that policy, programming, and research must be premised on social inclusion so that issues such as community integration, belonging, participation, overcoming discrimination and stigma, and other measures of quality of life are adequately addressed. There are inequalities of resources and power that make some people vulnerable

to homelessness or reduced life opportunities. This social injustice has multiple causes and consequences that reflect or affect many aspects of public policy and social relations.

There is a common assumption in our society that homelessness is caused by personal irresponsibility, often attributed to life choice, mental illness or substance abuse. While these negative perceptions that focus on the personal aspects of homelessness prevail, the structural causes can be overlooked. Behavioural factors may influence why any one individual with an ARBI can become homeless, and these require specific interventions; however, structural factors can often determine the aggregate level of social exclusion, service inequity and homelessness experienced. An important consequence is that these structural problems require a broad range of non-housing as well as housing interventions if they are to be remedied.

After almost a decade of inadequate government-supported housing programs and the increasing economic pressure of rising housing costs, an intractable contribution to homelessness has emerged from the dearth of low-cost housing. A recent Commonwealth Government Social Housing Initiative made the commitment to, with the assistance of the not-for-profit sector, build or renew social housing dwellings<sup>157</sup>. This initiative will make a positive contribution to the chronic shortage of affordable housing; however, very little additional funding has been committed to the provision of care and support to vulnerable people moving into these homes.

The inability of individuals to access appropriate support while living in the community can eventually result in homelessness or premature entry into residential aged care. Admission to a residential care facility that is unable to provide appropriate support to someone exhibiting complex and challenging behaviour can further lead to homelessness or admission to increasingly restrictive residential environments (e.g. locked wards, incarceration etc).

Demographic trends indicate that progressively more aged people will present to residential care with increasingly complex care needs including mental illness, cognitive impairment and behavioural problems. Australia's aged care workforce is currently inadequately skilled and funded to meet the increasing number of residents with higher and more complex care needs which add to the workloads of care staff in residential care settings. Indeed, the ratio of staff to residents has undergone very little change over time despite the increasing proportion of residents classified as requiring 'high care'.

Therefore, within the service industry, the risk of violence (physical assault, verbal aggression or emotional abuse) in the workplace is also of increasing concern. Inadequate staffing levels, inappropriately skilled staff and inadequate organisational support can place staff at higher risk of experiencing job dissatisfaction, burnout and workplace injuries. The provision of quality care requires adequate staffing levels with an appropriate skills mix and improved working relationships between health and social care services.

These workplace and workforce issues call for collaboration and input from all levels of government, in partnership with front-line care providers, professional organisations and other stakeholders. The challenge of aligning efforts across organisational, jurisdictional and philosophical boundaries will need to be addressed as will the funding shortfall to aged care service providers that care for people living with challenging behaviours and complex care needs. A system of financial allowances supported by an indexation system that keeps pace with the need to maintain wage parity could go some way in addressing this issue.

Another area of disadvantage to services supporting people living with an ARBI lies in the shortfall of funding and recognition within the field of social research. Government-funded research

grants currently disadvantage smaller not-for-profit organisations that wish to undertake social research based on interventions that are individualised to meet client support needs. Individualised psychosocial programs do not fit neatly into the scientific methodologies called for in funding applications. Complex interventions consisting of multiple behavioural, technological, and organisational components pose special evaluation problems because their components may act independently or interdependently, and it is often difficult to tease out the relationships between them. This has led to well documented difficulties in evaluating such interventions. Individualised programs do not fit neatly into scientific or clinical research models which evaluate change in response to interventions with set and prescribed independent variables.

Over recent years social research based on psychosocial interventions and qualitative methodologies are increasingly being recognised in the research fraternity as valid evaluative models; however, much of the administrative requirements contained within grant applications are still geared toward traditional empirical research methodologies. Much of the application process is premised on an academic understanding of research, which occurs within a theoretical and critical framework and based on hierarchical structures in scientific communities.

96

The application processes are extremely complex demanding a considerable investment of time, skills and coordination. Most grants stipulate the requirement for applicants to match dollar for dollar the value of grant monies received, which for most not-for-profit companies is usually unattainable. Most Government grants require the inclusion of academic partners from academic institutions and the engagement of principal investigators with successful track records in competitive grant funding and who have achieved national recognition as an expert within a field of research relevant to the application.

This complex process-driven system may prove totally overwhelming to a small not-for-profit company whose fundamental aim is to partner reciprocal services in the establishment of a valid evidence-base to use in support of quality improvement and best practice. As a result, research funding opportunities are generally limited to smaller philanthropic trust or community grant programs. Very often the monies available through these grants are inadequate to support larger partnership projects involving complex service delivery and evaluative components.



## 7 Conclusion

This action research successfully designed and implemented intervention strategies that supported older people with complex needs to transition and remain out of homelessness. We have shown that the provision of appropriate care and support will lead to improved life quality and wellbeing among a group of older people living with an ARBI. They drink less, smoke less, are less depressed, less anxious and are healthier. All this can be achieved with considerable cost savings to Government as compared with individuals living within the community who frequently access crisis and emergency services in the pursuit of having their needs met. The finding of a significant relationship between the number of days participants resided in the Wicking Household and increases in levels of productivity and community integration indicates that Wicking Model participants engaged more in meaningful social and physical activities.

Through this project, successful interventions and outcomes were achieved even for homeless individuals living with significant levels of cognitive impairment. A major consideration in the provision of appropriate care to an older homeless population is that they are not a homogeneous population. Flexible service systems, integrated health and psychosocial services provided by a multidisciplinary team, and client-centred care were all fundamental factors to the success of this project. Engagement in a therapeutic relationship based on trust and the development of a care plan influenced, where possible, by the participant's own perception of what constitutes wellbeing and life quality, were essential to this process.

The importance of ascertaining the participant's cognitive ability was shown to relate directly to the effectiveness of the project intervention. Deficits in a person's memory, perception, judgement, planning, and speech can result in poor problem-solving and social skills, and in his/her inability to make sound decisions. Executive impairments such as these also commonly result in difficulties with behaviour regulation, which can include difficulties with initiation (i.e. adynamia) and impulse control. If a person is to change their life circumstances, learn new skills and break destructive patterns of behaviour, an ability to learn, problem-solve, self-monitor and regulate their behaviour is required. This project has shown that despite the presence of these deficits, a psycho-social model of intervention that maximises an individual's strengths and compensates for their weaknesses can effectively improve life quality and wellbeing.

On face value, the outcomes of The Wicking Project may seem unremarkable. If you provide a vulnerable and socially isolated individual with security of tenure, engross them in a nurturing and socially rich environment; address the symptoms of ill-health, provide good food and facilitate access to appropriate support services, they are likely to improve physically, socially and mentally and begin to value their own self-worth. What is remarkable is why appropriate services are currently inaccessible to vulnerable older Australians? With the wealth of services, skills and expertise available, why do mainstream and specialist services continue to deliver a poorly coordinated and unintegrated response to homelessness, mental illness and drug addiction among the elderly?

With additional funding we hope to investigate these applications further in the future. Future considerations would be to examine how these research findings can be applied to more realistically reflect intervention effectiveness when elements of environment and systemic landscape are addressed. Several mechanisms for continuity are suggested, such as portable supports and developing offsite partnerships with community-based agencies that would stay with a person and act as an adjunct to linked supports. Integrated team models could provide layers of support in coordinated seamless service delivery. The processes of attaining and maintaining appropriate supports should follow a client through the transition of levels of care in a person-centred model of delivery. In this model, coordinated interdisciplinary teams could provide a combination of care

across a number of residential settings and onsite service staff would be trained to develop skills that improve the quality of care delivered in support of older people with complex and challenging needs.

The problem of elderly homelessness remains and people are still experiencing difficulty accessing mainstream services on a daily basis. The underlying cause of these obstacles is multifactorial including issues of discrimination, reluctance to engage, inappropriately skilled frontline service personnel, failures in service integration and the failure of policy to achieve its goals of recognition and responsiveness. Due to the complex characteristics of the client population, the provision of appropriate support services frequently extends well beyond the requirements and funding capability of most mainstream aged and community services.

The Wicking Project has taken the first step toward increasing awareness of the issues facing older people living with an ARBI and providing evidence of the gaps that exist for these people within the current service system. It has highlighted the need for specialised care and support and the significant positive effect that such support, when delivered in an appropriate and effective manner, can have on enhancing the life quality and wellbeing of this vulnerable and often neglected group of people.

## APPENDIX A

## The Story of Malcolm

Malcolm came to Wintringham from a major public hospital for respite care in November 2002. 'Post-acute Care Funding' was used to support this care in a Wintringham Hostel. Initially, very little information on Malcolm's turbulent life history was provided although his behaviour during the respite period was not remarkably different to that of his fellow Wintringham residents.

Toward the end of the respite period Malcolm's Advocate Guardian requested Wintringham continue to provide care on a semi-permanent basis. When Malcolm realised that he might stay for an extended period of time, his behaviour immediately began to deteriorate. Despite the hostel having historically demonstrated a capacity to manage elderly residents with relatively high behavioural care needs, Malcolm's additional multiple medical conditions meant that his care would require significantly greater resources than the hostel was capable of providing. As a 'last ditch effort' to find a solution, the Alcohol Related Brain Injury Assessment Service (arbias) managed to secure three month 'special circumstance' funding from the Department of Human Services to assist Wintringham in providing the appropriate level of care.

Malcolm was of Pacific Island origin, had two failed marriages, two children to his first wife and a brother. All of these relatives were living in Australia and all were estranged from him. One of his daughters cited her reason for the estrangement stemmed from issues relating to his alcoholism.

Malcolm presented as a charming man when he was not under the influence of alcohol although he incessantly sought ways to procure alcohol, continually neglected his dietary restriction resulting in poor diabetic control and was non-compliant in the self-administration of his medication. He persistently eluded his carers and on the numerous occasions when he was successful, he would either be found by staff or police in an intoxicated state or return to the hostel on his own extremely intoxicated. Very often he would end up in hospital as a result of injuries sustained while intoxicated or in a state of un/semi-consciousness secondary to his diabetic state.

Malcolm was seen on several occasions begging for money at a nearby tram-stop in order to buy alcohol and/or cigarettes. Alternatively he would steal alcohol from the local bottle shop either alone or in collaboration with others or 'butt stoop' (pick expended cigarette butts up off the ground).

In order to elude regular evening room checks for contraband, Malcolm would hide bottles of alcohol in nearby neighbour's rubbish bins awaiting a later retrieval. When Malcolm focused his attention on drinking excessively, any source of alcohol would suffice. He had been reported drinking methylated spirits and was observed by staff going to petrol stations and drinking the last petrol remaining in the bowser's nozzle and hose.

Malcolm's history showed that The District and Regional Hospitals had considered him to be a 'pest' and an 'over-user' of their services and therefore initiated the process of appointing an Advocate Guardian as they believed he posed a risk to himself and others. As well as multiple emergency department presentations, Malcolm frequently required inpatient care in hospitals for various issues including management of poorly controlled insulin-dependent diabetes, multiple fractures due to being struck by a motor vehicle while intoxicated and various other injuries sustained from falls.

Malcolm had lived a transient lifestyle with a long history of unsuccessful accommodation placements. Reports and file notes regarding previous accommodation described various incidents with comments including – "nearly burnt the place down in a drunken rampage"; "found unconscious in a diabetic coma"; "he caused havoc", "he even ripped the palings off the fence so that he could get to the pub", "his stay there lasted only six weeks before he was asked to leave".

Malcolm's Advocate Guardian reported that Malcolm had last lived alone in a flat in Melbourne's south-eastern suburbs and received community home support. The In-The-Home Care organised by his local Council and Royal District Nursing Service (RDNS) had been cancelled due to behavioural concerns and poor, non-compliant self-care practices. The In-The-Home Care Service stated that Malcolm was, "no longer capable of looking after himself in his own home".

Malcolm had been described as impulsive, lacking insight, angry, a thief, a beggar, a compulsive liar, a morbid alcoholic, manipulative, in denial, a gross under-reporter of his alcohol consumption.

In 2003 Malcolm was interviewed as a participant in an international study in which Wintringham was

a collaborative partner. Even though he acknowledged that he was a drinker and the consumption of alcohol was detrimental to his health, he did not associate his drinking with his financial difficulties or the breakdown of his marriages and family relations. When asked about what made him happy, Malcolm's first response was "To be at home with my wife and children living in the eastern suburbs (his first wife to whom he was married for 18 years), then he quickly added, "Although I know that this is not possible. My wife could not cope with me being sick because I kept collapsing in diabetic comas". When asked if alcohol contributed to the relationship breakdown he dismissed the suggestion stating that he only had a few glasses of wine each day, mainly while he cooked. When asked "What else makes you happy Malcolm?" He replied "I like cooking especially French and Pacific Island food and I enjoy sipping wine while I cook. I enjoy videos especially horrors, thrillers and martial arts movies and I enjoy going out to the pub for dinner and playing pool. I'm not great at pool though I'll give it a good go. I used to love dancing rock and roll. I'm a good dancer. I used to dance with my wife at cultural community functions though I have lost contact with these friends now and my health stops me from dancing. I'm not getting any younger."

Malcolm expressed frustration with his life circumstances and that he felt as though he was "being controlled". "Having been through this now, I never want to be in this situation again" he said. He said that he now had the incentive to look after himself with assistance from his doctor, his brother and his church and then perhaps he could even re-establish a relationship with his eldest daughter. He explained that his church forbade the consumption of alcohol which had resulted in his feeling of guilt and remorse especially after an episode of binge drinking.

Malcolm was asked how much alcohol he would need to sustain him and prevent him from seeking more. He suggested 5–6 glasses of wine a day and if left to his own control, Malcolm said that he would sip his wine every now and then throughout the day but not drink to excess.

When asked as to what his good qualities were, Malcolm replied, "My charm, my smile, my ability to converse, to go along with conversations and to share my views. I am a good listener."

Most of Malcolm's family had refused to re-establish contact with the exception of his brother who initially took Malcolm out on the occasional Saturday to attend the church and to share dinner. But unfortunately Malcolm experienced a hypoglycaemic episode during one of these outings and his brother no longer felt confident to accept the responsibility of his care. As a result contact with Malcolm's brother decreased to occasional visits at the hostel.

One day Malcolm received good news from another family member that his daughter was expecting a child. Malcolm was excited about the prospect of becoming a Grandfather and looked forward to the upcoming birth, as his daughter had promised to visit Malcolm with her baby. The prospect of this visit excited him immensely and he made the promise to 'behave' himself in the meantime so as not to jeopardise this long-awaited reunion.

Malcolm's individualised care plan included one-on-one time spent with a carer. This was best managed between the hours of 2.30pm and 9.00pm. The selection of times were influenced by Malcolm's medical requirements (insulin administration), staffing rosters, being able to ensure that Malcolm's dietary requirements were met, being able to facilitate evening outings including occasionally going out for dinner and to encourage and oversee personal care routines. Malcolm's carers employed techniques of compromise, reward and consequences to manage his behaviour. His one-on-one routine was well established by this time with the most favoured activity being a trip to the local pub for a beer and a game of pool. Malcolm's carers had come to accept that there would be times when Malcolm's psychological need for alcohol would exceed negative consequences.

A typical day for Malcolm started with glucose testing and supervised self-administration of insulin at 7.30am and then Malcolm slept before breakfast during which he was encouraged to help in the kitchen. After breakfast he helped to tidy his room and prepare lunch. At 2.30 his allocated carer teamed up with him to begin the scheduled activities. Activities included bus outings to places of interest, going to play billiards at the local hotel, dinner at McDonald's and video nights. Medication was administered again at 7.30pm and Malcolm was assisted with his personal hygiene and preparation for bed at 9.00pm. He usually watched TV before sleep. Scheduled activities would change according to weather



conditions, Malcolm's glucose levels and day-to-day organisational and staffing issues.

Malcolm's life was becoming more settled. It was difficult to identify whether this improvement was attributable to the effect of improved health or to the staff's ability to avert disruptive behaviour through the individualised behavioural care plan. The staff were increasingly adept at identifying the initial signs and exasperating triggers for challenging behaviour. However, despite the relative calm, there were occasional digressions. The most common of which was to elude his carer in order to procure alcohol.

Generally Malcolm was identified as not posing a risk to other residents or carers, however there was at least one reported incident of inappropriate sexual behaviour toward a female carer. This prompted a redesign of Malcolm's care plan with an avoidance of carers who met a profile, particularly females who were placid in nature or with whom Malcolm had had previous 'run-ins' or altercations. The most appropriate allocation of carers was refined as the care plan progressed. It was soon discovered that due to Malcolm's unrelenting demands on care staff during his 1:1 sessions, any one carer would not be assigned to his care for more than two days in a row. The staff were reported by the Hostel Manager to have 'burned out' after this length of time. A pool of six staff members was recruited to care for Malcolm on a rotating roster basis.

It was not long before Malcolm adopted a feeling of self-importance as a result of his involvement in his individualised care plan. He was reported on many occasions as saying, "It's time for my one-on-one" or "I am a special needs person". He thrived on the interaction and used this time to repetitively relay stories of his past hardships seeking encouragement and reassurance. Malcolm had a choice of activities undertaken during his one-on-one sessions; however he and was encouraged to invite other residents to join him if desired. Sometimes he would choose to invite other residents yet there were times when he wanted the carer's undivided attention. Having the power to choose his companions appeared to reinforce Malcolm's feelings of self-importance. As with staff, care was taken not to expose the other residents to a 'Malcolm overload' by encouraging his choice of companion or choice of activity and ensuring that the other residents had the freedom to choose whether they wanted to attend.

Not long after the commencement of Malcolm's individualised care plan, hostel staff noted a change in the morale and behaviour of other residents living in Malcolm's proximity. In fact, all residents were affected to some degree. Some aspects were positive such as the opportunity for other residents to share in some of the recreational activities planned for Malcolm. Some of the negative aspects included having to put up with Malcolm's challenging, repetitive behaviour and the unpredictability of his decision as to whether others could 'join him' and who he would 'select or allow' to participate. The major negative consequence of Malcolm's care plan was the perception that Malcolm was being rewarded for 'bad' behaviour. Other residents resented this and were jealous that Malcolm received so much attention. In turn, the behaviour of some residents deteriorated impacting on general morale and staff resources.

Malcolm's health had stabilised. His glucose levels, though still prone to large variations, had not exceeded manageable levels for over three months. Within this period he had not been admitted to hospital. This was a significant achievement compared with previous hospital admissions averaging three times per week. His diet and general disposition had improved considerably with established friendships with fellow residents. He was frequently reported to have been heard singing and continued to receive great pleasure in cooking for the other residents and staff. Malcolm was involved in establishing and regularly tending to a herb garden which, now in full bloom, provided fresh ingredients to his cooking.

## APPENDIX B

## Wicking Project Participant Consent

**PARTICIPANT INFORMATION AND CONSENT FORM****Version 3. Dated 17th June, 2008****Full Project Title: Older People with Acquired Brain Injury and Associated Complex Behaviours: An Evaluation of a Psychosocial Model of Care That Supports Long-term Residential Care Needs**

Principal Researcher: Dr Alice Rota-Bartelink

Associate Researcher(s): A Prof Mal Hopwood

This Participant Information and Consent Form is 6 pages long. Please make sure you have all the pages.

**1. Your Consent**

You are invited to take part in this research project.

102

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully together with your guardian (if appropriate). Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

**2. Purpose and Background**

The purpose of this project is to evaluate a novel form of residential care for older people living with severe acquired brain injury aiming to improve current residential care practices to better meet their care needs.

A total of 10 people will participate in this project.

Previous experience has shown that for years, community service providers have been frustrated with the lack of long-term specialised supported accommodation for older people with complex needs especially in the presence of the continued drinking of alcohol. If the needs of people with an acquired brain injury are not adequately met, the success of most currently available residential care options is low and people are forced to live in sub-standard accommodation.

You are invited to participate in this research project because your life experiences demonstrate that you have encountered difficulty in securing or maintaining accommodation because of your injury. You may also be a direct recipient of the new care model. Your participation in the care model does not depend on your participation in the evaluation.

**3. Procedures**

Participation in this project will involve

Committing to participate in an 18-month trial commencing in May 2008. During the trial you will either be: 1) housed together with 3 other people in a dedicated 4-bedroom home in Flemington; 2) or, one of six people who will be on a waiting list to enter the home should a vacancy arise.



As a potential participant in the evaluation you will be agreeing to allow us to exchange your personal information with your current service provider/s, which may be Wintringham Services.

If you are selected as one of the 10 trial participants, you will be requested to complete some assessments at the beginning of the trial and at 3 monthly intervals throughout the trial period. The initial and final assessments will take approximately three hours and the interim assessments will take approximately one hour. The findings will assist us in measuring changes in the quality of your life during the trial period.

#### **4 Possible Benefits**

Many people who have lived in crisis accommodation, rooming houses, cheap hotels, or on the streets often have lived a very hard life and through this they too have become hardened. Getting older, often makes living in these places more and more difficult. We want to provide these people with a dignified home and lifestyle where their needs are being met, yet they have to freedom to come and go as they please, to have a drink or two and to live a life that so many people take for granted. The trial household participants will have the opportunity to live in this environment while at the same time help us to learn exactly how to provide the best support to meet their needs. We can also not guarantee or promise that if you are in the control group that you will have the chance to move into the household. Involvement in the evaluation specifically may lead to direct benefit for the participant via the support available for this specific ongoing accommodation, but will also be of benefit for others with similar disability.

103

#### **5 Possible Risks**

The evaluation itself is considered unlikely to pose any risk to its participants beyond fatigue. You have the right to withdraw at any time from the evaluation.

#### **6. Privacy, Confidentiality and Disclosure of Information**

By signing this consent you agree to the exchanging/obtaining of personal information regarding the services you currently receive from care, support and welfare agencies with Wintringham for the purpose of assessing your eligibility for the project and for collection of data for the evaluation of the project.

Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. I understand that in accordance with the Privacy Act and the National Privacy Principles 1998 and Health Records Act 2000 that the information will be kept confidential and stored in a secure manner in a locked filing cabinet for a period of seven years. If you give us your permission by signing the Consent Form, we plan to share, discuss and publish the results with government department and community services. In any publication, information will be provided in such a way that you cannot be identified. There will be a requirement of the trial household participants that they sign a confidentiality agreement in which they agree that they, at no time during or after the trial, discuss any issues relating to another trial participant with anyone not directly connected to the trial.

#### **8. New Information Arising During the Project ?**

During the research project, new information about the risks and benefits of the evaluation may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs.

#### **9. Results of Project**

All trial participants will be provided with a copy of the final project report together with a plain English summary of the project's findings. Individual progress reports can also be provided to the participants upon their request.

## 10. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher or Mr Bryan Lipmann or Ms Helen Small at Wintringham Ph 9376 1122 or Associate Professor Mal Hopwood at Austin Health Ph 9496 2750. The researchers responsible for this project is Dr Alice Rota Bartelink on 9376 1122 or AH 0413 874 703 (Mc Lean Lodge).

## 11. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: **Mr Andrew Crowden**

Position: Chairperson Austin Health Human Research Ethics Committee

Telephone: 9496 2901

You will need to tell Mary the name of one of the researchers given in section 10 above.

104

## 12. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Wintringham or Austin Health Services.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

## 13. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Austin Health, for the trial which will be carried out at 11 Mooltan Street Flemington and administered through Wintringham Head Office at 136 Mt Alexander Road, Flemington 3031.

## 14. Reimbursement for your costs

You will not be paid for your participation in this project.

## CONSENT FORM

(Attached to Participant Information)

### Consent Form

Version: 3 Dated: 17th June, 2008

Site Wintringham

**Full Project Title: Older People with Acquired Brain Injury and Associated Complex Behaviours: An Evaluation of a Psychosocial Model of Care That Supports Long-term Residential Care Needs**

I have read, or have had read to me, and I understand the Participant Information version 3 dated 17th June, 2008.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Witness to Participant's Signature (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

Declaration by researcher\*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed) .....

Signature \_\_\_\_\_ Date \_\_\_\_\_

\* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.

### THIRD PARTY CONSENT FORM

*(To be used by persons responsible for the participant e.g. legal guardian)*

#### **(Attached to Participant Information)**

**Third Party Consent Form**  
**Version: 3 Dated: 17th June, 2008**

**Site** Wintringham

**Full Project Title: Older People with Acquired Brain Injury and Associated Complex Behaviours: An Evaluation of a Psychosocial Model of Care That Supports Long-term Residential Care Needs**

I have read, or have had read to me, and I understand the Participant Information version **3** dated **17th June, 2008**.

106

As the person responsible for the participant, I give my permission for **[participant's name]** to participate in this project according to the conditions in the Participant Information.

I will be given a copy of Participant Information and Consent Form to keep.

The researcher has agreed not to reveal the participant's identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed) .....

Name of Person giving Consent (printed) .....

Relationship to Participant: .....

Signature Date

Name of Witness to Parent/Guardian Signature (printed) .....

Signature Date

Declaration by researcher\*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the person responsible for the participant has understood that explanation.

Researcher's Name (printed) .....

Signature Date

\* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.

## APPENDIX C – Example of Drinking & Smoking Program

These programs and procedures were developed following considerable consultation with participants and staff involved in the Wicking Project.

**Table 7** Example of a Wicking Model Participant's Drinking Program

| Administration Time    | Resident | Alcohol                  | Cigarettes                                                                                                  |
|------------------------|----------|--------------------------|-------------------------------------------------------------------------------------------------------------|
| 10am                   | P1       | 140ml of wine            | Receives a daily portion of White Ox at the start of each day which he self administers throughout the day. |
|                        | P2       | 140ml of wine            | Purchases & self administers additional cigarettes.                                                         |
|                        | P3       | 140ml of wine            | Receives a packet of White Ox each Wednesday which he then self administers throughout the week.            |
|                        | P4       | 1 stubby                 | 1 cigarette                                                                                                 |
| 12noon                 | P1       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P2       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P3       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P4       | 1 stubby                 | 1 cigarette                                                                                                 |
| 4pm                    | P1       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P2       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P3       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P4       | 140ml of wine            | 1 cigarette                                                                                                 |
| 8pm                    | P1       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P2       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P3       | 140ml of wine            | Self administers as required.                                                                               |
|                        | P4       | 140ml of wine            | Self administers as required.                                                                               |
| 9pm<br>(or before bed) | P4       | No alcohol administered. | 1 cigarette                                                                                                 |

### Staff Guidelines

- It is essential that this program is followed with 100% consistency by all staff.
- Staff are to ask each participant whether they would like their alcohol rather than automatically giving it to them.
- Alcohol can only be administered at times specified above.
- Resident's must wait until the next administration time if they miss a drink.
- Resident's can accumulate missed drinks to a maximum of 3 drinks on the one occasion, However missed drinks cannot be accumulated and consumed the following day.  
Note: if giving more than 1 drink, supply in different glasses.
- Offer alcohol even if the participant has consumed additional alcohol outside of their program.
- Only 1 day's allocation of alcohol to be kept within the house. The remainder will be kept externally.

Wicking Residence overnight staff member to:

*Prior to commencing sleepover*

- Remove any alcohol that wasn't consumed that day from The Wicking Residence and return it to external store.
- Decanter the alcohol for each participant for the next day into individual one-drink sized containers and ensure that containers are clearly labeled with the participant's name and time of administration.

*First thing in the morning*

- Place the daily allocation in the locked fridge in The Wicking Residence for distribution throughout the day.



## APPENDIX D

## Wicking Project Correlation Findings

- 1 Higher levels of depression as measured by the Hospital Anxiety & Depression Scale (HADS) are significantly associated with a lower gain in number of life roles ( $r=0.709, p=0.032$ ).
- 2 Higher levels of depression as measured by the Hospital Anxiety & Depression Scale (HADS) are significantly associated with an increase in the level of problem drinking as determined by the Alcohol Use Disorders Identification Test (AUDIT) ( $r=0.616, p=0.033$ ).
- 3 Higher level of anxiety as measured by the Hospital Anxiety & Depression Scale (HADS) are significantly associated with an increase in the level of problematic drinking as determined by the AUDIT ( $r=0.622, p=0.013$ ) and self reported number of drinks consumed per day ( $r=0.820, p=0.001$ ). Within groups this relationship was only significant for the Wicking Model Participants ( $r=0.881, p=0.020$ ).
- 4 Increases in the level of home integration as measured by the Community Integration Questionnaire (CIQ) was significantly associated with a decrease in the number of cigarettes smoked each day ( $r=0.820, p=0.001$ ).
- 5 Increases in the number of days residing in the Wicking Household is significantly associated with greater productivity levels as determined by the Community Integration Questionnaire (CIQ) ( $r=0.733, p=0.004$ ).
- 6 Satisfaction With Life scores as measured with the Satisfaction with Life Scale (SWLS) was significantly associated with an earlier age of commencement of drinking ( $r=0.62, p=0.02$ ).
- 7 Lower life satisfaction scores showed a weaker relationship with increasing levels of problematic drinking as measured by the AUDIT ( $r=0.774, p=0.55$ ) and greater number of drinks consumed each day ( $r=-0.784, p=0.065$ ).
- 8 Increased Neuropsychiatric Inventory Scores (NPI) measuring both the severity and impact of behaviours share a significant relationship with increases in challenging behaviour as determined by The Overt Behaviour Scale Total Scores (OBS) ( $r=0.707, p=0.007$ ), OBS Clinically Weighted Scores ( $r=0.768, p=0.002$ ) and a reduced number of life roles ( $r=0.910, p=0.032$ ).
- 9 Increased Overt Behaviour Scale Total Scores (OBS) were significantly associated with a greater number of cigarettes smoked each day ( $r=0.557, p=0.048$ ) and shared a weaker relationship with a reduced number of life roles ( $r=0.867, p=0.057$ ).
- 10 Within the Wicking Model Group only:
  - Increases in Community Integration Questionnaire scores in the domains of social integration and productivity are significantly associated with decreases in problematic drinking as determined by the AUDIT. ( $r=0.758, p=0.048$ ) and ( $r=0.806, p=0.029$ );
  - Increases in years of schooling were significantly associated with the attainment of a greater number of life roles ( $r=0.900, p=0.037$ ).

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# Wintringham



## **Wintringham**

ABN 97 007 293 478

Head Office  
136 Mt Alexander Road  
PO Box 193  
Flemington Victoria 3031

T 03 9376 1122

F 03 9376 8138

E [admin@wintringham.org.au](mailto:admin@wintringham.org.au)

I [www.wintringham.org.au](http://www.wintringham.org.au)