Wintringham
SPECIALIST AGED CARE

The Dementia and Veterans' Supplements in Aged Care – Consultation Paper - (April 2013)

Wintringham's Comments and feedback

17 May 2013

OPTIONS · DIGNITY · RIGHTS ·

Contents

PREFACE

Wintringham welcomes the opportunity to comment on The Dementia and Veterans' Supplements in Aged Care - Consultation Paper - (April 2013).

Wintringham's response will concentrate exclusively on the elderly homeless, an area in which we have widely acknowledged expertise. We will demonstrate that many in our client group require the Dementia Supplement discussed in the Consultation Paper. Some of the responses that we have developed to the problem of delivering services to aged men and women who are homeless have clear implications to the development of a range of programmatic policy settings for the delivery of aged care services to all elderly people who do not fit neatly into existing mainstream groups.

Wintringham is pleased that there is formal acknowledgement within the Consultation Paper that residents' behavioral care needs have not been adequately supported financially. We are encouraged that the Department is formally attempting to address the well documented shortfall of funding that ACFI has presented to Wintringham clients. Wintringham believes that the proposed Dementia Supplement will go some way to resolving this funding shortfall and remain confident that the Department will continue to work with Wintringham on any remaining funding gap.

It should be noted that Wintringham has made a recent submission to the Senate Standing Committee on Community Affairs regarding the Aged Care (Living Longer Living Better) Bill 2013. In it we argue for a Financial Viability Supplement that will bring Homeless aged care providers back to equity with funding for the rest of the aged care industry:

> *… the Aged Care Act has essentially been designed around the needs and resources of an elderly Australian who has little in common with a homeless person. Homeless people cannot pay Accommodation Bonds (except in the most unusual circumstances), rely solely on the Aged Pension and usually have no additional financial resources with which to make any additional contribution, and in the main, have no family upon whom they can rely for either emotional or financial support.*
>
> *Organisations such as Wintringham, who work exclusively with the elderly homeless, can therefore rely on no income stream other than government recurrent funding. Up until 2008, this was delivered by the RCS (Resident Classification Scale).*
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> *Wintringham's financial records and analysis shows that under the RCS system and in the years preceding the introduction of ACFI, we earned on average about $90 a day per resident which was equivalent or perhaps $0.50 cents above the national average RCS figure. Although we had a far more complex client group, many with alcohol related brain injuries and associated behavioural problems, and received very few Accommodation Bonds, the income earned from the RCS was sufficient for Wintringham to remain financially viable.*

> *Under ACFI, however, our income dramatically fell largely due to the different weighting the instrument placed on ADLs (Activities of Daily Living) as distinct from behavioural interventions.*

Our submission to the Senate has sought to bring us back to the funding baseline we dropped below when ACFI was introduced. We anticipate that a solution can be found in the form of a Financial Viability Supplement.

We welcome this opportunity to join with the rest of the aged care industry to look specifically at the financial and care implications of severe and complex behaviours, both in the residential care and community care settings, and assist in finding a workable Dementia Supplement to address the critical issues raised in the Consultation paper.

Wintringham's experience in working with clients that the mainstream aged care sector regularly rejects will be shared in this submission. We will highlight concerns we have with the workings of the proposed Dementia Supplement for our client group.

Wintringham: some background information

Wintringham was established in 1989 as an independent not-for-profit welfare company to provide high quality aged care services to frail elderly homeless men and women. Today we provide a range of services to approximately 1,300 elderly people who are homeless or at risk of becoming homeless each night, including low and high care residential homes, community care packages, State funded support packages, a range of housing services and options, street based outreach work, advocacy services, as well as our work representing the interests of the homeless elderly on a variety of State and national ministerial advisory committees. More details about these services and further background to the company can be found at www.wintringham.org.au.

Wintringham is today the largest provider of services to the elderly homeless in Australia. Of the approximately 700 residential aged care beds in Australia, Wintringham has more than 200 reserved exclusively for the homeless. In addition to the four Registered Aged Care Facilities (both low and mixed care) Wintringham has designed and build the first nursing home for homeless people in Australia, and quite possibly the first one in the world.

In 2011, Wintringham was award the United Nations Habitat Scroll of Honour, the first time an Australian organisation has achieved this award which is the highest award for human settlement provided by UN-Habitat.

The vision at the start of Wintringham was simple. The company would be a social justice organisation that would care for older homeless people whom the aged care industry had turned its back on.

Our view of social justice, and the rights that flow as a result of social justice, is that aged care and housing are basic and fundamental rights and should not be consequential on the personal values of a worker or an organisation. So, for Wintringham, older homeless people have a right to decent aged care services and housing simply because they are Australian citizens.

The elderly homeless remain one of the most disadvantaged and powerless groups in Australian society. At a time of life when most people would be enjoying their retirement, elderly homeless men and women live outside mainstream society making do with inadequate food, clothing and housing.

Elderly and homeless: shifting the paradigm

At the time of the formation of Wintringham, many hundreds of elderly men and women were living and dying in homeless persons' night shelters unable to access mainstream aged care services even though these services were often run by Church and charitable organisations who received tax concessions in order to provide for the disadvantaged.

The prevailing view in the 1970's and 80's was that as these elderly folk were homeless, it was appropriate that they were in a homeless service. In short, these aged people were being seen as *homeless and elderly* and as such it was the responsibility of the homeless sector to provide for them. Wintringham reversed that expression, arguing that aged homeless people were *elderly and homeless.*

Changing the description of aged homeless people from being *homeless and elderly* to *elderly and homeless* is not merely semantics: it creates a new paradigm and a new way of thinking about the elderly homeless. It involves acknowledging that the person is aged and therefore entitled to normal aged care services. If we say they are homeless it perhaps makes some sense of the fact that they are living in a homeless persons' night shelter, but if we say that they are aged (and just happen to be homeless) then the next question surely is "why are they not part of the aged persons' service system?"

The principle that Wintringham has operated on from its inception is that the aged homeless should have the same right as any other elderly Australian to access mainstream aged care services.

The aged care system is not allowed to discriminate against any minority group on the basis of their ethnicity, religion or personal views. Why then should they not be required to make welcome the elderly homeless?

Unable to place our elderly homeless clients in mainstream aged care services, Wintringham resolved to build its own.

Is there a typical Wintringham Client?

Wintringham's residents and clients do not fit the profile of a 'typical' mainstream aged care resident who is around 87 years of age, female, likely to have been referred to a care option by an Aged Care Assessment Service and originating from a middle class background. On the contrary, Wintringham residents are predominantly male, the median age is 66 years and they are almost exclusively from the working class.

As a consequence of a homeless lifestyle, Wintringham clients and residents have an over-representation of people with the following characteristics:

- No regular contact or support from family and friends and no record of a next of kin.
- A need for guardianship support through the Office of the Public Advocate (OPA). Approximately 50% of newly admitted Wintringham residential aged care residents receive guardianship support.
- A need for administrative and financial support. Approximately 70% of newly admitted residents to Wintringham residential aged care services are under Administration Orders.
- High incidence of psychological illness and/or acquired brain impairment and or social/behavioural issues (various forms of dementia / intellectual disability). Acquired brain injuries can cause symptoms similar to psychosis and dementia, as well as significant problems with impulse control, social skills and self-awareness.
- Premature ageing – 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.
- Poor skills in activities of daily living leading to domestic mismanagement.
- Unwillingness to readily engage with services and participate in communal activities.
- High prevalence of issues relating to gambling, drug and alcohol addiction and abuse.
- High prevalence of challenging, difficult and anti-social behaviours. Challenging behaviours are generally described as behaviours that, either directly or indirectly, seriously disrupt or affect the lives or routines of other people or services. In the residential setting these include other residents, neighbours, support services, staff, families and communities. Frequently the presence of these behaviours interferes with the resident's ability to learn, and may place the person, others or property at risk of injury or damage.
- It is well documented that people who are homeless have higher rates of illness, drug dependency and injury than the general population.
- The majority of our clients have some sort of diagnosable condition including mental illness, drug and alcohol disorders, behaviour disorders, and intellectual disability as well as chronic health problems. Many have had multiple and uncoordinated interactions with a variety of services, including emergency services.
- There are also significant health problems generally linked to poor nutrition occurring secondarily to alcohol addiction.

It is well documented that excessive drinking over a period of years may lead to a condition known as Alcohol Dementia, which can cause problems with memory, learning and other cognitive skills. Alcohol has a direct effect on brain cells, resulting in poor judgment, difficulty making decisions and lack of insight. Nutrition problems often accompany long-time alcohol abuse and can be another contributing factor, since parts of the brain may be damaged by vitamin deficiencies.

Wintringham clients suffering from dementia may have very little ability to learn new things, while many of their other mental abilities are still highly functioning. Along with the decline in cognitive skills, sometimes noticeable personality changes take place. As many of our clients who drink may have a concurrent mental health issue, it is not

uncommon for them to have diagnosis of Alcohol Related Brain Injury or Alcohol Related Dementia as well as other mental health issues.

'Dual diagnosis' describes people who have coexisting substance abuse (drug and/or alcohol problems) and mental illness or psychiatric disability. Homeless persons who are dually diagnosed with severe mental illness and substance use disorders constitute a particularly vulnerable subgroup with complex care needs. These patients have been shown to have a poorer prognosis than patients with exclusive substance addiction, with a higher incidence of hospitalisation, medication non-compliance, criminality, homelessness, and suicide. Because of such complicated diagnostic and morbidity issues, patients identified as having dual or multiple diagnoses require specialised treatment for a successful outcome. In turn, individuals with multiple care needs require a wider suite of service provision for longer periods of time.

Residents and community clients coping with these health and social issues have posed many unique challenges to services such as Wintringham that are only occasionally experienced by other aged care providers.

THE DEMENTIA AND VETERANS' SUPPLEMENTS IN HOME CARE PACKAGES

Wintringham are appreciative that new home care packages will be supported with a behaviour-based Dementia Supplement. We believe many of our clients should be entitled to the Dementia Supplement as most of them have behaviours of concern. We congratulate the department on recognising that clients with behaviour issues present a higher cost of care for service providers at all care levels.

Of concern to Wintringham is the reliance on the Psychogeriatric Assessment Scales (PAS) as the preferred tool for assessing community clients' behavioural care needs. While we understand that PAS may well work in a mainstream client cohort, we are not satisfied that it is reliable with homeless clients who have atypical forms of dementia. As detailed elsewhere in this submission, Wintringham has a high proportion of clients with behaviours of concern that are more related to brain injury, particularly Alcohol Related Brain Injury. As such we are concerned that the use of PAS exclusively for assessment of behaviour with community clients may inadvertently discriminate against our client's behavioural care needs.

Since the introduction of ACFI in Residential Aged Care, our clinical and care staff have found the PAS to be unreliable in terms of predicting our residents' behavioural care needs. Department representatives have themselves acknowledged our concerns with using PAS for our client group during 2009 – 2010 when a full ACFI review occurred at Wintringham.

Further to this, the Psychogeriatric Assessment Scales User Guide indicates that sufficient data has not yet been collected to use the PAS reliably for people with alcoholic dementia (which constitute a large cohort of Wintringham's clients). (http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-pas-guide.htm)

RECOMMENDATION 1

Wintringham advises that the PAS is not a valid assessment tool for homeless clients with an alcohol related brain injury or dementia. We would ask that DoHA works with Wintringham to determine a more appropriate assessment tool or method.

We also note that the guidelines currently specify that behavioral assessment must be undertaken by a registered nurse, clinical nurse consultant, nurse practitioner or medical practitioner. Wintringham clients are supported in the community by Case Managers who have an approved tertiary qualification in Social Work, Nursing, Allied Health or Welfare. Given the expertise of our current case management group with extreme behaviors, Wintringham hopes that greater flexibility to who may complete the assessment will be offered. We believe there will be an unnecessary additional cost impost for some providers to be compliant with the draft behavioral assessment expectations.

RECOMMENDATION 2

Wintringham requests that further consideration be given to the eligibility of professionals who may undertake behavioural assessment, so that it may include individuals with tertiary qualifications working for specialist providers who have receive annual training in behavioural management techniques.

Finally, Wintringham believe that a Dementia Supplement of 10% of the value of the clients' package will go some way to assist clients with behavioral care needs to remain in a home like environment. We do remain somewhat apprehensive that the 10% behavioral subsidy may be insufficient to fully compensate for the specialised care needs of clients with severe and complex behaviours and psychological symptoms associated with dementia and mental illness.

RECOMMENDATION 3

Wintringham request that DoHA remain open to further discussions surrounding the possible need for an additional 'Severe Behaviour' Supplement for clients that may fit into this category.

THE DEMENTIA SUPPLEMENT IN RESIDENTIAL CARE

Wintringham congratulate the Department for attempting to rectify the concerns Wintringham have consistently expressed; that the Aged Care Funding Instrument (ACFI) does not fully capture people with severe and complex behaviors. The description of the high behavioral need client in the discussion paper is one of a typical Wintringham resident!

Having said that, Wintringham again remains apprehensive that the Supplement will not fully resolve the funding shortfall Wintringham have experienced with its client group since the introduction of ACFI and expect that the quantum of $16.25 a day will fall short of the fully addressing the funding shortfall we have experienced.

The process for identifying residents with severe behavioural needs appears flexible and the mental and behavioural conditions listed in **Appendix B** appears to capture the majority of behavioral conditions of clients who present to Wintringham.

RECOMMENDATION 4

Wintringham understands the need for a new assessment tool to adequately assess severity of behaviours. We have limited experience with using the *Neuropsychiatric Inventory – Nursing Homes (NPI-NH)* assessment tool and trust the Department will remain open to feedback on the effectiveness of the tool in regard to adequately capturing Homeless clients' behavioural needs.

We also note that the assessment must be carried out by a registered nurse, clinical nurse consultant, nurse practitioner, medical practitioner or specialist trained in the application of this tool and where it is within their scope of practice. Wintringham's care staff are highly trained in the management of behaviors of concern and we believe they could be trained in the use of the *Neuropsychiatric Inventory – Nursing Homes (NPI-NH)* assessment tool which would prevent a cost impost of employing specialist to conduct such an assessment

RECOMMENDATION 5

Wintringham requests that further consideration be given to the eligibility of care staff who may undertake behavioural assessment, so that it may include individuals working for specialist providers who receive annual training in behavioural management techniques.

Although Wintringham has had significant problems with the ACFI and how it unintentionally discriminates against homeless clients that have a relatively low requirement for assistance with Activities for Daily Living (ADLs) but who often have high behavioural issues, we have strongly advocated against any changes to ACFI. Our experience is that it would be extremely difficult to quarantine any changes to ACFI that could be limited to our client group and not bleed-out to the industry as a whole.

The funding shortfall we have experienced since the advent of ACFI remains, however, of critical importance to Wintringham's ongoing viability.

RECOMMENDATION 6

Wintringham request that DoHA continue to treat separately negotiations for a Financial Viability Supplement for beds provided for the Homeless to negotiations around the Dementia Supplement discussed in this Consultation Paper. The Financial Viability Supplement is needed by Homeless residential care providers to bring us back to parity with the rest of the aged care industry. The

Dementia Supplement is needed by any aged care provider who cares for residents and clients who exhibit Severe Behaviours.

Finally, the Department has requested feedback on whether it is necessary to expand the eligibility requirements for the Dementia Supplement to ensure that the additional funding is only provided to Approved Providers who can demonstrate they have the capacity to deliver appropriate care for residents with severe behavioral and psychological symptoms.

Wintringham, together with the Federal Government, established in 1989 the right of Elderly Homeless people to access the mainstream aged care system. While that victory for homeless people is still resonating around the aged care community, a fundamental problem continues to plague the delivery of these services. The problem is that the aged care system and all of the various alterations, additions, reforms and innovations are designed around the needs of an elderly person who has little in common with a homeless person.

Wintringham have always hoped that Aged Care Providers as a whole would willingly provide care an options for the elderly homeless. The fact that Wintringham has been so successful as a company is indicative that Aged Care Providers have generally failed to make welcome homeless clients into their service.

The Dementia Supplement may go some way to address this issue, but Wintringham remains concerned that the type of client we believe the Dementia Supplement is trying to support may not reflect true admission changes without some further Department overview that ensure that the additional funding is only provided to Approved Providers who can demonstrate they have the capacity to deliver appropriate care for residents with severe behavioral and psychological symptoms.

RECOMMENDATION 7

That the Department remain open to review the introduction of the Dementia Supplement to ensure the Supplement supports those clients it was intended for.

SUMMARY

Wintringham congratulates the Department on the introduction of the proposed Dementia and Veterans' Supplement as an important step toward addressing the financial consequences of caring for people with severe and complex behaviours in both residential and community aged care settings.

We are eager to work with the Department in refining the assessment instruments and methods of implementation of the Dementia Supplement.

In the Residential Care setting, we continue to argue for a Financial Viability Supplement to bring Wintringham back to a funding baseline we dropped below when ACFI was introduced. We believe that this shortfall was unintentional and has not been introduced

to penalise homeless providers. Nevertheless, the burden that this has placed on homeless aged care providers threatens our ongoing viability and our capacity to provide care to the elderly homeless.

We trust the department will continue to work with us to resolve the funding shortfall issue.

Bryan Lipmann, AM

Chief Executive Officer

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