Submission to the Ministry of Health

on the

Secure Dementia Unit Design Reference Guide

26 April 2016

Introduction

1. This submission is from the New Zealand Aged Care Association (NZACA), the peak body for the aged residential care sector, and the Retirement Villages Association (RVA), the peak body for the retirement village industry. The submission has been informed by input from our respective memberships, some of whom may have lodged submissions directly with the Ministry of Health (MOH). In a few cases our members have sent us their submissions directly and where this is the case these are attached to the submission.

About the NZACA

2. The NZACA represents 90% or approximately 33,500 beds of the country's aged residential care (ARC) sector. NZACA members range from the very small stand-alone care homes to the large co-located sites that include care services and retirement villages. Our members' services include rest home, hospital, dementia and psychogeriatric care, as well as short-term respite care.

3. Advocating and lobbying to government to shape policies and create an environment that helps our members provide outstanding quality care is at the heart of what we do. We also provide leadership on issues that impact on the success of our members, for example, the work we are currently doing on the Equal Pay Case. We also produce valuable research, professional development opportunities, information and publications to help our members make informed business decisions, improve capability and keep them up-to-date with sector developments.

4. The NZACA has a small Wellington based team led by Chief Executive Simon Wallace, a representative Board of 10 members chaired by Simon O'Dowd and a network of 14 branches around the country.

About the RVA

5. The RVA represents the owners, developers and managers of retirement villages throughout New Zealand. The 340 member villages have around 25,500 units that are home to approximately 35,000 older New Zealanders. This is around 95% of the registered retirement village units.

6. The RVA's interests in this matter are driven by the fact that almost all residential care beds, including dementia beds built new over the last six years or so have been part of a registered retirement village. This means that the RVA's members are providing the capital to build the facilities, although their day-to-day operation, under the terms and conditions of the Age Related Residential Care (ARRC) Services Agreement, lie with the NZACA. Informal research also suggests that anything up to 30% of "independent" residents in a village are in the early stages of dementia.

7. Any enquiries relating to this paper should in the first instance be referred to Simon Wallace, NZACA Chief Executive at simon@nzaca.org.nz or by phone on 04 473 3159, or to John Collyns, RVA Executive Director at john@retirementvillages.org.nz or by phone on 04 499 7090.

Executive Summary

8. This paper highlights the key issues of concern that both our organisations see with the proposed Secure Dementia Unit Design Reference Guide (Reference Guide). Our comments are largely consistent with the position that we have already articulated in meetings with

officials and correspondence with Ministers over the past few weeks and months. These comments are expanded upon in the submission, but in short:

- A case for change has not been made given the already high quality of dementia care services in New Zealand.
- There has been no consideration given to cost for our members and the fiscal pressure on government.
- The impact on models of care has not been assessed.
- Standards or de-facto standards are being applied as though they are requirements.
- The consultation process has been poor and lacking in objectivity.

9. We note that the document name has been changed from Guidelines to Reference Guide, but critically the Guide itself states that "the Ministry may audit the provider against this Guide to determine whether the reconfiguration will meet relevant standards" (footnote, p.4), a position that has been supported by officials. This confirms our earlier views and does not allay our concerns that the Reference Guide will be used by auditors in the certification of our members' businesses.

Comment

Some useful tools

10. The overarching reasons for this Reference Guide are to promote high quality care for residents who live in secure dementia units. This is a principle that all our members subscribe to and in this regard there is much in the Reference Guide that is of use, especially around the environmental and aesthetic elements. For example, there is little to argue with on matters such as:

    - memory aides
    - colours
    - sound
    - lighting and
    - use of familiar pictures, books and objects

11. Some of our members do have different opinions on particular aspects of the Reference Guide. For example, the Eden Greenhouse model has proven the benefit of bedrooms being off living spaces (p. 12), while built in furniture (p. 12), not necessarily free standing wardrobes and shelves, are actually what we see in our own homes. Examples like this lend weight to the countervailing views that have been expressed by our members on some parts of the paper.

12. There are many helpful references in the Reference Guide to person-centred care which is not only at the heart of what our members do, but is a key pillar of the just released New Zealand Health Strategy. That said, we do believe that the Reference Guide could be strengthened to reflect the new and welcome focus on person-centred care. For example, the NZACA now prefers to use the words 'care home' rather than unit or facility as a way of personalising how we perceive the environment in which our residents live.

A case for change has not been made

13. We believe a case for change has not been established by the work that has gone into this Reference Guide. For a start, no analysis has been made of the clinical indicators within secure dementia units or more broadly across the ARC sector to determine what the prevailing concerns are. For example, we have seen no evidence from consumers (families/friends/whanau) that the system is 'broken'.

Cost to members and fiscal pressure to government

14. Despite our concerns, officials have repeatedly said they will not undertake any economic analysis of their proposals, even they though they agree (as noted in the Reference Guide) that there could be a financial impact. Both the NZACA and the RVA recommended at an earlier stage that an extra step be built into the process to include an assessment of the financial impacts, but despite our repeated suggestions, we were told by officials that such considerations were out of scope.

15. As we have said in correspondence to Ministers, we believe it is unreasonable that the sector has to provide its own economic analysis in support of the status quo when the MOH, which wants to impose potentially sweeping changes in this area, refuses to undertake even the most rudimentary analysis of its own proposals. By way of example, the Reference Guide states that "a 20 resident was presented as the minimum affordable stand-alone unit and is the current indication in the ARRC agreement, however, no economic analysis was presented in support of this".

16. The ARC sector operates in a capped funding environment that does not give us the ability to make the design changes proposed within existing budgets. There will be fiscal pressure on the government as a result of these changes, but crucially too the Reference Guide will risk investment and innovation in dementia services right across the sector, from small to large providers, at a time when the incidence of dementia is increasing because of a fast ageing population. This could undo the benefit gained from increased dementia care capacity that has come about as a result of the National-led Government's dementia funding initiatives over recent years.

The impact on models of care

17. Design is not the only consideration of outstanding dementia care and this work appears to place a bias on the built environment without recognising the time and investment our members make in staffing and training to deliver the person-centred care of which we are so proud.

18. The Reference Guide appears to ignore that the aged care industry is more broadly a people industry – it is the many dedicated staff in our care homes and retirement villages, such as nurses, caregivers, cooks, cleaners, gardeners, the many other support workers and allied health professionals who do more to enhance the quality of life for our residents than the designed or built environment.

19. The Reference Guide also lacks fundamental analysis of how a recommended unit size of between six to fourteen residents (page 32) will impact on staffing, not to mention economics.

Standards or de-facto standards applied as though they are requirements

20. Past experience tells us that guidelines can have a habit of becoming a regulatory standard or a 'de-facto' standard, a most recent example of this being the medication guidelines that became auditable. If these guidelines were to become an auditable standard (refer footnote on page 4) then not only would this require more resource for the government and HealthCERT, it would place extra cost on our members without the commensurate change in funding to the ARRC Services Agreement.

Perverse outcome

21. Our early analysis of the interRAI Annual Report (released on 18 April 2016) shows that more than half (52%) of long term care facility (LTCF) assessments show these people with either Alzheimer's or another form of dementia diagnosis, some of whom will be living in rest home or hospital care. In view of this we need to be mindful of not creating an environment that provides a differentiated level of care between rest home and hospital residents and those living in secure dementia units.

The consultation process

22. The consultation process has been lacking in many respects. While there may have been many individuals (as listed on page 49), who attended the workshops around the country, there would have been some clinical and operational staff who would not have wanted to disagree with the proposals in such a public forum. In addition, we know of at least one senior sector representative who is listed as attending when he didn't.

23. The obvious exclusion of any financial analysis in this work (a point that was not made clear in the initial scope) is a failure of the process and one that exposes the government and our members to fiscal pressure.

Judicial Review

24. The NZACA and the RVA are currently seeking advice on a judicial review of the process for the development of the Reference Guide.

Conclusion

25. To sum up, our organisations believe the Reference Guide needs a lot more work before it is fit for purpose. We have noted the many useful aspects of the report with regard to aesthetics and person-centred care and these are welcomed. However, the report falls short in several areas, notably its failure to assess the fiscal pressures that will be created for government and our members, a single-minded focus on design that ignores not only the operational impact on our staffing, but that people are at the centre of outstanding dementia care and services. Until further work can be done to address these areas, we believe the document should be labelled a resource or a discussion document with the removal of any reference to auditing.

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