ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

SUBMISSION OF THE AUSTRALIAN NURSING AND MIDWIFERY FEDERATION

INTRODUCTION

1. This submission concerns younger people living in residential aged care facilities (RACFs).

2. This submission is provided in response to the matters the Royal Commission will inquire into at the public hearings to be held in Melbourne between Monday 9 September 2019 and Friday 13 September 2019. It addresses:

   - The impact that living in residential aged care has on younger people.
   - Understanding the drivers which result in younger people being admitted into and staying in residential aged care.
   - The appropriateness of the allocation of policy responsibility in this area to the health system, social services system and aged care system.
   - How best to support people who wish to leave residential aged care.

3. This submission focuses on these issues from the perspective of Australian Nursing and Midwifery Federation (ANMF) members' delivery and/or involvement in care for younger people living in RACFs.

The AUSTRALIAN NURSING AND MIDWIFERY FEDERATION (ANMF)

4. The Australian Nursing and Midwifery Federation (ANMF) is Australia's largest national union and professional nursing and midwifery organisation. In collaboration with the ANMF's eight state and territory branches, we represent the professional, industrial and political interests of more than 275,000 nurses, midwives, and care workers across the country.[1]

5. Our members work in the public and private health, aged care, and disability sectors across a wide variety of urban, rural, and remote locations. We work with them to improve their ability to deliver safe and best practice care in each and every one of these settings, fulfil their professional goals, and achieve a healthy work/life balance.

6. Our strong and growing membership and integrated role as both a trade union and professional organisation provide us with a complete understanding of all aspects of

[1] Care workers can be referred to by a variety of titles, including but not limited to 'assistant in nursing', 'personal care worker' and 'aged care worker'. In Australia, these staff are unregulated in contrast to registered nurses and enrolled nurses. For the purposes of this submission, workers who provide assistance in nursing care within RACFs are referred to as care workers.

the nursing and midwifery professions and see us uniquely placed to defend and advance our professions.

7. Through our work with members we aim to strengthen the contribution of nursing and midwifery to improving Australia's health and aged care systems, and the health of our national and global communities.

8. The ANMF represents almost 40,000 nurses and care workers working in the aged care sector, across both residential and home and community care settings.

9. The ANMF's position is that all residents of aged care facilities should have access to and experience safe, best practice care regardless of their location, health conditions, personal circumstances, and background.

10. Nurses and care workers are central to the provision of care encompassing all aspects of health care as well as in providing clinical and functional assessments and assistance and support with activities of daily living. This includes health promotion, prevention of illness and injury, care of the ill, disabled and dying. Care should be evidence-based, person-centred, and holistic in addressing physical, mental, social, and emotional wellbeing and should also be delivered in a manner that is appropriate and consistent with the individual preferences, values, and beliefs of each person.

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

11. In line with the terminology of the Australian Government's Department of Social Services term, in this submission 'younger people in RACFs' are defined as being people aged under 65 years of age that live in RACFs. As at 30 September 2018, the Department of Health reported that there were 5,905 younger people in RACFs across Australia of which 188 were aged under 45 years of age.[2]

12. Overall, the ANMF's position echoes that of the Senate Reference Committee articulated in their report following an inquiry into quality and equity in aged care:[3]

> *"Young people should not be in aged care facilities as these facilities and services are designed for, and respond to, the needs of the frail elderly. Elderly residents have care needs, health needs and social needs which are quite different from young people."*

13. The ANMF agrees that RACFs are largely inappropriate contexts for the provision of safe, quality, holistic and person-centred care for many residents who are younger,

---

[2] Department of Social Services. 2019. Younger people in Residential Aged Care (Internet). Australian Government. Available online: https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative

[3] Senate Reference Committee. 2005. Chapter 4: Young people in residential aged care facilities. Parliamentary Inquiry into Quality and equity in aged care 2005 [Internet]. Parliament of Australia. Available online: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/aged_care04/report/c04

and that more appropriate services must be developed as a matter of priority. Residential aged care facilities are generally not designed, staffed, or organised in a way that facilitates or enables appropriate, safe, effective care for younger people. In the absence of more appropriate services, there are still many younger people in and who will continue to be admitted to RACFs, so until better models of care can be rolled out, it is vital that RACFs should be able to provide the best possible care to all residents regardless of age and background. This means that RACFs require an adequately sized workforce with the right skills-mix and type of staff to care for younger people and address the diverse personal and clinical needs and preferences for care they have.

14. Each year, approximately 2,000 younger people are admitted permanently to RACFs; around half of this figure are aged between 60 and 65 years of age.[4] The three most common health conditions experienced by younger people in RACFs are cancer, cerebrovascular disease, and dementia. While dementia is less common among the youngest RACF residents than among older residents, progressive neurological conditions are more common.[5]

15. Aboriginal and Torres Strait Islander people are disproportionally represented among younger RACF residents and appear to be the youngest group upon admission.[6] One in ten RACF residents aged under 50 are Aboriginal or Torres Strait Islander people.[7] On average, Aboriginal and Torres Strait Islander people in RACFs are younger than non-Indigenous people; 26% of Aboriginal and Torres Strait Islander people living in RACFs are aged under 65 years of age in comparison with 3% or less for non-Indigenous people.[8] At 30 June 2018, just over 7% of Aboriginal and Torres Strait Islander people in RACFs were aged under 55 years in comparison with 0.6% of non-Indigenous people.

16. Among younger people living in RACFs, men represent 3% of people aged 60-64 years of age while women represent 1% of this age group.[9]

17. Younger people in RACFs may have considerable limitations regarding activities of daily living, with one in four experiencing an activity limitation in all four core activities (self-care, communication, movement between locations and moving/walking around). Self-care limitations (such as difficulty with eating or getting dressed) are experienced by around 90% of younger people in RACFs.[10]

---

[4] Australian Institute of Health and Welfare (AIHW). 2019. Pathways of younger people entering permanent residential aged care. Cat. no. AGE 89. Canberra: AIHW. Available online: https://www.aihw.gov.au/getmedia/c43debe7-cc79-401e-b028-6d0859d9d802/aihw-age-89.pdf.aspx?inline=true

[5] Ibid.

[6] Borotkanics R, et al. 2017. Changes in the profile of Australians in 77 residential aged care facilities across New South Wales and the Australian Capital Territory. *Australian Health Review.* 41(6):613-20. Available online: https://www.publish.csiro.au/ah/Fulltext/AH16125

[7] Ibid.

[8] Australian Institute of Health and Welfare. 2017. People using Aged Care (Internet). Australian Government. Available online: https://www.gen-agedcaredata.gov.au/Topics/People-using-aged-care

[9] Ibid.

[10] Ibid. [4].

18. Despite the challenges and limitations faced by younger people in RACFs, many younger residents are more physically fit than older, more frail residents and therefore have different and individual needs regarding cognitive, physical activity, and rehabilitative care requirements. Younger people in RACFs tend to require a greater number of staff hours to have their care and support needs adequately met, highlighting the issues around ensuring an adequate number of the right skills mix of direct care staff to provide for these needs.[11] As the Senate Reference Committee noted, staffing in RACFs are:[12]

> *"...*[N]*owhere near to being adequate for the different and more intense needs of young people with complex care needs."*

19. Despite the fact that younger people in RACFs may be more physically fit than older residents, the quality of life of younger residents may be poorer than older cohorts.[13,14]

20. Mental health and suicide prevention is an area where there may be important differences between younger and older RACF residents. Among the differences between younger and older residents, higher odds of dying from suicide has been found to be associated with people aged under 65 years of age.[15] This was an unexpected finding from a recent Australian study, as most residents are aged 85 years or greater and also have the highest rates of suicide in the community. The authors highlight that this finding may be partly attributable to the generally greater physical fitness of younger residents and the increased risk of death by other causes among older (85+ years) residents. Further research into suicide amongst both younger and older RACF residents is necessary to identify effective approaches to prevention.

21. Younger people may not be adequately or appropriately cared for within the context of RACFs which have not been designed or developed to be suitable for this diverse group of people. The social and emotional environment within RACFs may not be appropriate or suitable for younger people in these facilities, as they may have different and individualised desires and needs regarding entertainment, activities, exercise, sexuality, and socialising. One study in Victoria regarding the social contact, participation, recreation, and community access of 330 people under 60 years of age

---

[11] Vossius C, Selbaek G, Saltyte Benth J, Wimo A, Bergh S. 2019. The use of direct care in nursing home residents: A longitudinal cohort study over 3 years. *International Journal of Geriatric Psychiatry.* 34(2):337-51. Available online: https://doi-org.access.library.unisa.edu.au/10.1002/gps.5026

[12] Ibid. [3].

[13] Lai CKY, Leung DDM, Kwong EWY, Lee RLP. 2014. Factors associated with the quality of life of nursing home residents in Hong Kong. *International Nursing Review.* 62(1):120-129. Available online: https://doi-org.access.library.unisa.edu.au/10.1111/inr.12152

[14] Kuok CF, et al. 2017. Quality of life and clinical correlates in older adults living in the community and in nursing homes in Macao. *Psychogeriatrics.* 17(3):194-9. Available online: https://doi-org.access.library.unisa.edu.au/10.1111/psyg.12214

[15] Murphy B, Bugeja LC, Pilgrim JL, Ibrahim JE. 2018. Suicide among nursing home residents in Australia: A national population-based retrospective analysis of medico-legal death investigation information. *International Journal of Geriatric Psychiatry.* 33(5):786-96. Available online: https://doi.org/10.1002/gps.4862

in Victorian RACFs found that many people were isolated from peers, with only 44% receiving a visit from a friend less frequently than once per year.[16] Sixteen per cent of residents participated in a recreation activity less than once per month and 21% went outside less than once per month. Of the sample, 34% almost never participated in any community-based activities such as shopping, leisure or visiting friends and family. Likewise, the built environment of RACFs may not be suitable for younger residents who may have different needs regarding physical space and privacy.

22. Intimacy and sexual health needs are at risk of being ignored among people in RACFs as generally, older peoples' sexuality and sex lives are overlooked.[17] Sexuality and sexual health of people in RACFs is a topic that has been frequently overlooked but which is now gaining greater attention and interest. The needs, preferences, and attitudes to sex and sexuality for both older and younger people in RACFs deserves attention and consideration and can be a common area where care can fall short.[18] A recent survey found that most residential aged care staff do not have access to policies on sexuality or sexual health to guide their practice.[19] Nurses can play a key role in ensuring RACFs provide an environment that is supportive of residents' rights, needs, and desires regarding sex, sexuality, and sexual health.[20] By including recognition of sex and sexuality in overall understandings of life satisfaction and care planning, the holistic care needs and preferences of residents is better able to be met. With the understanding that each and every resident, regardless of age, may have different and unique needs and preferences regarding sex and sexuality, those of younger people in RACFs may be different from older people. Aged care providers must include a thorough assessment of sexual health of residents in routine practice and include sexual health in care planning.

23. Younger people in RACFs may require different considerations to be made regarding their family's involvement in their care. It is important that RACFs are able to effectively involve family members in the care of younger residents in line with their own needs and wishes as well as the best available evidence in terms of safety, quality, and effectiveness.

---

[16] Winkler D, Farnworth L, Sloan S. 2006. People under 60 living in aged care facilities in Victoria. *Australian Health Review.* 30(1):100-8. Available online: http://www.publish.csiro.au/AH/AH060100

[17] Doll GM. 2013. Sexuality in nursing homes: practice and policy. *J Gerontol Nurs.* 39(7):30-7. Available online: https://doi.org/10.3928/00989134-20130418-01

[18] Aguilar RA. 2017. Sexual expression of nursing home residents: systematic review of the literature. *J Nurs Scholarship.* 49(5):470-7. Available online: https://doi.org/10.1111/jnu.12315

[19] McAuliffe L, Featherstone D, Bauer M. 2018. Sexuality and sexual health: Policy in Australian residential aged care. *Australas J Aging*. [E-Pub ahead of print]. Available online: https://doi.org/10.1111/ajag.12602

[20] Roach SM. 2004. Sexual Behaviour of nursing home residents: staff perceptions and responses. *J Adv Nurs.* 48(4): 371-9. Available online: https://doi.org/10.1111/j.1365-2648.2004.03206.x

24. Supporting the results of previous research,[21,22] a large study from the United States using minimum dataset evidence from 2005 – 2015 found that people who are classed as obese in RACFs are more likely to be younger and to have greater direct care needs and time with staff than other residents.[23] For people aged younger than 65 years of age in RACFs, the prevalence of obesity was observed to increase from 36.5% in 2005 to 41% in 2015. Further, these younger people are likely to remain in RACFs longer due to lower mortality rates. Combined with rising overweight and obesity rates in the broader community, this means that it is likely that the prevalence of obesity will continue to increase in RACFs. This trend is likely to be replicated in Australia due to similar increases in overweight and obesity rates. People who are obese tend to have a greater number of comorbid conditions and also may require greater assistance with activities of daily living including getting out of bed, moving around, bathing, and toileting. The authors of the study highlight that obese residents have greater direct care needs and time with nurses and care workers than other residents. Aged care staff who care for residents who are obese require additional assistance and support to safely aid residents – this may include special devices to assist residents to move and also extends to ensuring that there are enough staff to safely move residents when one or two staff members may not be able to by themselves. Lifting and moving heavy residents can cause injury; either to the resident or the staff member. In the National Aged Care Survey 2019, our members highlighted the problems they faced around safely moving heavier residents in the context of inadequate staff numbers, limited access to appropriate equipment, and unfair legislation regarding work-related injuries:[24]

    - *"As a* (registered nurse) *and the manager of a facility I know that we cannot deliver the care that is required, and that people deserve. The significant change in resident needs over the last 5 years now means that for most residents 2 people are required for manual handling and at least 30-40% require assistance at meal times and the current challenge is ensuring we can get people fed. With people coming into care at the mid-point or later in their dementia journey means that behaviours are more complex and require even greater skill sets then presently available and more people to manage them. If we had more hands and eyes on the floor we would have less falls, less instances of aggressive behaviour, greater participation with people and teams, less skin tears, and more stable weights."*

---

[21] Harris JA, Engberg J, George Castle N. 2018. Obesity and intensive staffing needs of nursing home residents. *Geriatric Nursing*. 39(6):696-701. Available online: https://doi.org/10.1016/j.gerinurse.2018.05.006

[22] Kosar CM, Thomas KS, Gozalo PL, Mor V. 2018. Higher Level of Obesity Is Associated with Intensive Personal Care Assistance in the Nursing Home. *Journal of the American Medical Directors Association*. 19(11):1015-19. Available online: https://doi.org/10.1016/j.jamda.2018.04.013

[23] Zhang N, Field T, Mazor KM, et al. 2019. The increasing prevalence of obesity in residents of U.S. nursing homes: 2005-2015. *The Journals of Gerontology: Series A*. Available online: https://doi-org.access.library.unisa.edu.au/10.1093/gerona/gly265

[24] Australian Nursing and Midwifery Federation (ANMF). 2019. ANMF National Aged Care Survey 2019 - Final Report [Internet]. Australian Nursing and Midwifery Federation (Federal Office), Melbourne, Victoria. Available online: http://anmf.org.au/documents/reports/ANMF_Aged_Care_Survey_Report_2019.pdf

- *"Business managers are dictating heavy excessive workloads, buying cheap unsafe products and making safe manual handling impossible as no different coloured slide sheets are available to ensure everyone is pulling using the top sheet. The standards are criminal. There needs to be wardsmen per institution ratios to help with an aging bariatric workforce as the workforce is also aging but workplace designs are poor. Suction equipment is ground height, staff are shifting heavy equipment to make room for more patients when demands increase, staff are missing meal breaks daily, but it all looks very economic for business managers forcing injury costs to workers using "onus of proof" legislation. Even if they have an incident at work, the employee with be blamed for not using inaccessible lifting equipment, or paperwork will be fudged. there will definitely be no investigation because nurses are disposable."*

- *"*(E)*specially high levels of work related injuries paid for by the injured workers because "onus of proof" legislation discriminates against manual handlers doing repetitive lifting and bending in poor ergometric environments with heavy patients and poor quality products."*

25. As the population of people experiencing homelessness ages, an increasing number of these people require care, some may enter RACFs.[25] In one study from the United States, veterans who were homeless in the year prior to entry into an RACF were younger (62.5 years/Standard Deviation (SD) = 10.3 years) than stably housed residents (75.3 years/SD = 11.9 years).[26] Residents who were homeless have different characteristics to stably-housed residents and were also more likely to have a diagnosis of alcohol abuse, drug abuse, mental health conditions, dementia, liver disease, and tri-morbidity. These complex conditions can be challenging for RACF staff, especially where staffing and skills-mixes are poor, leading to too few staff with the clinical and specialist expertise to provide safe, quality care or adequate integration with and handover to medical, allied health, and social services specialists.

26. There is currently a "homelessness supplement" for RACFs that specialise in caring for people with a history of, or who are at risk of, homelessness.[27] Currently, providers must have more than 50% of all residents meeting the viability expansion component and homeless supplement assessment criteria in order to be eligible for the supplement. While this supplement is necessary to support the additional care requirements that many people who experience homelessness/ unstable housing and other commonly associated co-occurring conditions, limiting the supplement to

---

[25] Homelessness Australia. 2016. Homelessness and older people. Homelessness Australia. Available online: https://www.homelessnessaustralia.org.au/sites/homelessnessaus/files/2017-07/Homelessness_and_Older_People.pdf

[26] Jutkowitz E, Halladay C, McGeary J, O'Toole T, Rudolph JL. 2019. *Journal of the American Geriatrics Society*. 67(8):1707-1712. Available online: https://onlinelibrary-wiley-com.access.library.unisa.edu.au/doi/full/10.1111/jgs.15993

[27] Department of Health. 2016. Aging and Aged Care: Homeless Supplement. Australian Government. Available online: https://agedcare.health.gov.au/aged-care-funding/residential-care-subsidy/supplements/homeless-supplement

RACFs with 50% or more eligible residents may not adequately incentivise the provision of care to these people, who are also likely to be younger than the general RACF population, in facilities where there are fewer than 50% of residents with a history of, or who are at risk of, homelessness. This may be a particular problem in areas with limited availability of RACFs, such as in regional and remote areas where homelessness is rising.[28]

DRIVERS OF AGED CARE FACILTY ADMISSIONS FOR YOUNG PEOPLE

27. There are a range of drivers/factors that lead to younger people to be admitted into RACFS. Many of these factors are interrelated and operate in an additive fashion where combined, they may increase the probability of a person requiring admission to an RACF. For example, an Aboriginal person living with a disability that impacts upon their ability to undertake activities of daily living unsupported, who has a history of unstable housing in a remote location may be at a higher risk of RACF admission than someone with only one of these factors.

28. Most younger people who enter an RACF appear to have a relatively 'simple' pathway, with 23% having not had experience with any other aged care prior to their first admission. The most common pathway (38% of younger people) was being admitted to a permanent RACF place following receipt of home and community care. Of those younger people who received home and community care who do not immediately enter an RACF permanently, 14% received a period of respite care prior to permanent RACF admission. A quarter of younger people entering permanent RACFs for the first time follow a different more complicated pathway which are described in greater detail in the AIHW report.[29]

29. A considerable driver of admission into an RACF is due to the lack of appropriate accommodation facilities or lack of beds within such facilities available that provide care more specifically to younger people who may need the level of care that can generally only feasibly be offered in a residential setting. This can also extend to existing suitable facilities not being able to offer respite services for younger people who need higher levels of personal or clinical care on a temporary basis, such as while their normal care provider is unable to care for them or following a specific event where increased care is required. Closure of existing facilities (e.g. the Halwyn Centre in Queensland) that provide care to younger people can increase the likelihood of residents having to move into RACFs when they cannot receive safe, appropriate care in the community due to care needs, mismatch of funding, or lack of respite services to care for new residents.[30]

---

[28] Parkinson S, Batterham D, Reynolds M, Wood G. 2016. The Changing geography of homelessness: a spatial analysis from 2001 to 2016. Australian Housing and Research Institute. Available online: https://www.ahuri.edu.au/__data/assets/pdf_file/0010/40402/The-changing-geography-of-homelessness-a-spatial-analysis-from-2001-to-2016-Executive-Summary.pdf

[29] IBID. [4].

[30] ABC News. 2019. Queensland residential disability centre to stay open but families remain fearful. Australian Broadcasting Corporation. Available online: https://www.abc.net.au/news/2019-04-18/families-sceptical-qld-health-minister-halwyn-centre-decision/11026400

Disability

30. Having a disability, most commonly from a catastrophic injury (e.g. an acquired brain injury from for example a car accident or sporting injury) or a progressive neurodegenerative disorder (e.g. Multiple Sclerosis, Parkinson's and Huntington's disease) is the primary reason why younger people may be admitted into an RACF. Medical technology, automotive safety, and health care advances have meant that more people survive through the acute stages of a traumatic injury or are able to live for longer with a neurodegenerative disorder. However these people may require life-long health, every day, and social support to maintain an acceptable and deserved quality of life. This, still diverse, group of people are likely to have a considerable need for high-level care despite being younger and having longer life expectancies. Many younger people with a traumatic brain injury or neurodegenerative disorder require ongoing high levels of care but do not have significantly reduced expected life-spans. This means that a younger person in an RACF may need to remain there for many years longer than the "average" older resident whose stay is around 2.5 years from admission.[31] For example, of the 1,909 younger people who first entered permanent residential aged care in 2009–10, almost 500 (25%) were still in permanent care up to nine years later at 30 June 2018.[32] Younger people who have experienced a traumatic brain injury resulting in RACF admission can have negative experiences regarding living in RACFS; feelings can include not belonging in a terminal environment, confinement, disempowerment, emptiness and hope for greater autonomy through rehabilitation.[33] Aged care staff may require specific training to deliver evidence-based rehabilitative interventions to residents who have suffered traumatic brain injury, especially if purpose-designed alternative accommodation is not available.

31. When acute hospital care is no longer required, a younger person will be discharged but may not be able to return to their previous living circumstances for a range of reasons including; requirement for continual or frequent medical and clinical support or treatment, additional support for activities of daily living, inappropriate home environment (e.g. inaccessible bathrooms etc), lack of resources (e.g. assistance and health care technologies). While some younger people may be able to move back to their home environment, others may need the level of clinical and everyday assistance that may only be available in an RACF in the absence of other potentially more appropriate long-term care facilities.

32. Younger people may also be admitted into RACFs if their primary care provider/s are unable to continue providing the care they require in their own home in the community. For example, as people age or become unwell themselves, they may not be able to continue caring for a loved one who they may need to be admitted into an RACF.

---

[31] Australian Institute of Health and Welfare. 2017. People Leaving Aged Care (Internet). Australian Government. Available online: https://www.gen-agedcaredata.gov.au/Topics/People-leaving-aged-care

[32] IBID. [4].

[33] Dwyer A, Heary C, Ward M, MacNeela P. 2019. Adding insult to brain injury: young adults' experiences of residing in nursing homes following acquired brain injury. *Disabil Rehabil.* 41(1):33-43. Available online: https://doi.org/10.1080/09638288.2017.1370732

33. Intellectual disability may also be a driver for younger peoples' admission into RACFs.[34] People in RACFs with intellectual disabilities appear to be admitted younger, and also may remain in RACFs for longer than the general RACF population. People with intellectual disabilities in RACFs require holistic, person-centred care that is tailored to their unique needs and preferences, however this may not currently occur in all facilities as providers have highlighted concerns regarding inability of such people to fit in with the resident community, lack of participation in activities, and an absence of meaningful relationships.[35]

Being an Aboriginal and/or Torres Strait Islander Person

34. The numerous health and social disadvantages experienced by Aboriginal and Torres Strait Islander people result in the development of serious medical conditions at younger ages and lower live-expectancy than non-Indigenous people. Aboriginal and Torres Strait Islander people are eligible to receive home support at 45 years of age which may partially explain the larger proportion of Aboriginal and Torres Strait Islander People in this program. As the most frequent reason for leaving home support is admission to a RACF (56%), it is likely that many younger Aboriginal and Torres Strait Islander people entering RACFs move there from previous home support programmes.[36]

Homelessness or History of Unstable Housing

35. People who are aged 50 years or older and are "prematurely aged" (i.e. people whose life experiences, including active military service, homelessness, or substance abuse put them at risk of experiencing conditions or issues that normally occur at later ages for the general population) or on a low income may be eligible for assistance with care and housing services usually delivered under the Commonwealth home Support Programme.[37] This may lead to an increase in the number of younger people who are also homeless or who have unstable housing moving from home/community care to RACFs as their needs change and increase.

Impairment in Activities of Daily Living

36. People who experience impairment in activities of daily living (ADLs) such as bathing or dressing may have a greater risk of admission to an RACF at younger ages. In a study of 5,540 adults without impairment aged 50 to 56 years of age who were followed-up over time, 2,739 women and 2,801 men developed an ADL impairment between 50 and 64 years of age.[38] Those with ADL impairment were at a greater risk

---

[34] Bigby C, Webber R, Bowers B, McKenzie-Green B. 2008. A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *J Intellect Disabil Res.* 52(Pt 5): 404-14. Available online: https://doi.org/10.1111/j.1365-2788.2007.01040.x

[35] Ibid.

[36] Australian Institute of Health and Welfare. 2017. People Leaving Aged Care (Internet). Australian Government. Available online: https://www.gen-agedcaredata.gov.au/Topics/People-leaving-aged-care

[37] My Aged Care. 2019. Support for people facing homelessness. Australian Government. Available online: https://www.myagedcare.gov.au/support-people-facing-homelessness

[38] Brown RT, et al. 2019. Association of functional impairment in middle age with hospitalisation, nursing home admission, and death. *JAMA Internal Medicine.* 179(5):668-675.

of being admitted to an RACF as well as hospitalisation and death. This study highlights that younger people in RACFs, like older adults, may experience considerable functional impairments that restrict unassisted aspects of normal daily living. Adequate numbers and skills mixes of staff are therefore necessary to ensure that all residents, regardless of age, are provided with the support and care they require based upon their individualised needs.

Regional, Rural, or Remote Location

37. Younger people who may have otherwise been able to remain at home or in another supported care context may need to be admitted to an RACF due to their geographic location not affording adequate access to alternative care and support services.

Mental Ill-Health

38. Mental ill-health can be a factor for younger people being admitted to RACFs. Using national Minimum Data Set assessments from 2005, a 2011 study compared the demographic, clinical, and functional characteristics of people with and without serious mental illness newly admitted to RACFs.[39] Newly admitted residents with serious mental illnesses were younger and more highly likely to become long-stay residents than those admitted with other conditions. The authors highlighted that their results indicate that many, especially younger, RACF residents may have the functional capacity to live in less restrictive environments.

Younger Onset Dementia

39. Younger onset dementia (YOD) affects people under 65 years of age and can affect people who are in their 30s-60s. There is currently an estimated 27,247 people with YOD, which is expected to rise to 29,353 by 2028 and 41,249 people by 2058.[40] People affected by YOD can experience different psychosocial challenges in comparison to older people; coping with unforeseen decline in health and functional ability, impacts upon employment, parental and other caring responsibilities and relationships can be especially significant.[41] People affected by YOD can experience greater challenges with movement, balance, and coordination problems in earlier stages of the disease which may lead to increased risk of admission to an RACF.[42] Also, higher levels of apathy may also be experienced by people with YOD along with higher rates of psychotropic drug use and overall higher risk of developing neuropsychiatric symptoms than people with later onset dementia.[43] These differences are concerning due to the association between apathy and poorer

---

[39] Aschbrenner K, et al. 2011. Nursing home admissions and long-stay conversions among persons with and without serious mental illness. *J Aging Soc Policy.* 23(3):286-304. Available online: https://doi.org/10.1080/08959420.2011.579511

[40] Dementia Australia. 2018. Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra.

[41] Rayment D, Kuruvilla T. 2015. Service provision for young-onset dementia in the UK. *Prog Neurol Psychiatry*.19:28–30. Available online: https://doi.org/10.1002/pnp.391

[42] Alzheimer's Society of Great Britain. 2019. Young-onset dementia. Available online: https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia

[43] Appelhof B, et al. 2019. Differences in neuropsychiatric symptoms between nursing home residents with young-onset dementia and late-onset dementia. *Aging Ment Health.* 23(5):581-6. Available online: https://doi.org/10.1080/13607863.2018.1428935

quality of life, highlighting the need for tailored interventions for residents with YOD, such as more stimulating socio-therapeutic environments. For people under 65 years of age who live alone, there is a higher risk of moving into a RACF to receive the ongoing necessary care they require.

40. Age-appropriate services in RACFs for people with YOD are required. People with YOD in RACFs often experience a loss of autonomy and also report a lack of appropriate purposeful exercise and occupational activities as well as necessary emotional support.[44]

41. In the ANMF's previous submission to the Royal Commission regarding dementia care, we have highlighted the need for care that acknowledges the diverse needs and preferences of residents including younger people with dementia.[45] Our recommendations regarding improving care in RACFs for people with dementia highlighted in that submission are echoed here with a particular focus on younger people.

ALLOCATION OF POLICY RESPONSIBILITY

42. The complexity of care required by younger people in RACFs can be considerable. Effective and appropriate policy would support keeping younger people out of RACFs that are focussed upon caring for older residents and either in safe, quality community care or residential care that is more suitable and specifically focussed on the diverse needs and preferences of younger people.

43. Younger people in aged care often require services provided by health care, aged care, disability care, allied health care, and rehabilitation and among others. The interfaces between each of these sectors is often neither well-coordinated, nor clear. Fragmentation of services and poor articulation of policy can result in lack of coordination (e.g. due to the absence of a single case manager/navigator), difficulty navigating through and between services as well as confusion regarding funding. With the understanding that the current Australian RACF environment is generally not ideal or appropriate for many younger people receiving care there, it is important that multiple sectors work in partnership to ensure that future policy is improved to both ensure that where other accommodation is not available, RACFs are able to provide the best possible care for younger people, and that where possible, younger people are able to receive safe, high-quality care outside of RACFs.

44. The ANMF has already provided extensive evidence supporting the need for mandated minimum staffing and skills mixes in aged care. The ANMF advocates that to ensure that younger people in RACFs receive the quality of person-centred care they need and deserve, a suitable number and skills mix of staff is required. Policies that result in safe staffing levels in RACFs would go far in ensuring that there are

---

[44] Rimkeit S and McIntosh J. 2017. Experiencing place: younger people with dementia facing aged care. *Australas Psychiatry.* 25(6):554-61. Available online: https://doi.org/10.1177/1039856217706821

[45] ANM.0003.0001.0001 – Australian Nursing and Midwifery Federation (ANMF). Royal Commission into Aged Care Quality and Safety – Residential Dementia Care. ANMF. Melbourne, Australia.

enough staff with the right skills to appropriately care for all residents including younger people with complex health and personal care needs that can vary considerably from those of older residents and one another.

HOW BEST TO SUPPORT YOUNGER PEOPLE LEAVING AGED CARE

45. There is a broad and growing agreement that RACFs are not appropriate contexts for best-practice, safe, quality care for younger people and that alternative models of both residential and community care must be made more accessible. The National Disability Insurance Scheme (NDIS) is one avenue for addressing the movement of younger people from RACFs to more appropriate care, but efforts are still falling behind in terms of ensuring that NDIS plans are able to support younger residents to leave especially where there is poor availability or affordability of appropriate housing and lack of sufficient or suitable support for living in the community. Currently, only 2 out of 3 younger RACF resident with a disability are participating in the NDIS.[46]

46. In March 2019 the Australian Government announced that a national action plan had been developed to underpin the reduction in the number of younger people in RACFs though facilitation of access to more age-appropriate housing and supported living options. The action plan stipulated the following goals:[47]

    - Support existing younger people under 45 years of age in RACFs who desire to, to find alternative, age-appropriate housing and supports by 2022.
    - Support younger people aged under 65 in RACFs who desire to, to find alternative, age appropriate housing and supports by 2025.
    - Halve the number of younger people aged under 65 years of age entering aged care by 2025.

47. Between 2017-18, 1,853 younger RACF residents existed RACFs in Australia, while only around 10% returned to their family or another residence, over half died.[48] A recent systematic review of 35 studies found that most studies that examined the influence of age upon hospitalisation at the end of life reported that younger age was associated with a greater likelihood of end of life hospitalisation.[49] The frequency and wide variations regarding end of life hospitalisations across studies highlight that interventions targeted at supporting improvements in end of life care

---

[46] Bishop G M, Zail J, Bo'sher L, Winkler D. 2019. Young People in Residential Aged Care (2017 – 2018) A Snapshot [Internet]. Melbourne, Australia: Summer Foundation. Available online: https://www.summerfoundation.org.au/resources/young-people-in-rac-2017-2018/

[47] Australian Government. 2019. Younger People in Residential Aged Care – Action Plan (Internet). Australian Government. Available online: https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-action-plan

[48] Ibid. [40].

[49] Allers K, Hoffman F, Schnakenberg R. 2019. Hospitalizations of nursing home residents at the end of life: a systematic review. *Palliative Medicine*. Available online: https://journals-sagepub-com.access.library.unisa.edu.au/doi/full/10.1177/0269216319866648

must be tailored to different health and aged care systems. The authors recommended that countries with lower proportions of end of life hospitalisations should serve as examples to those with higher proportions and that targeted interventions such as advance care planning and palliative care should be adopted to improve end of life care in RACFs and to reduce unnecessary hospitalisations at the end of life.

48. Transitioning younger people out of RACFs will necessarily be gradual and also challenging in areas where resources and infrastructure are limited. Ultimately, it is of critical importance that younger people who require the level of health and personal care that currently can often only be delivered within the context of RACFs have a greater choice of other more appropriate residential facilities as well as much improved access to integrated health, welfare, and support services to receive care within the community.

49. While younger people are receiving care within RACFs, it is vital that the care they receive is provided by a suitably sized and equipped workforce with the right skills mix and education to deliver safe, quality person-centred care that is appropriate to the diverse and often unique needs of younger residents.