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Young people in Australian residential aged care: evaluating trends from 2008 to 2018

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Abstract.

Objective. Over the past decade, various programs and reforms have targeted the issue of people aged <65 years living in 'permanent' residential aged care (PRAC). As context for ongoing policy discourse, the aim of this study was to evaluate trends in rates of young people entering and leaving PRAC from 2008 to 2018.

Methods. Counts of people aged <65 years entering, remaining in and exiting PRAC were obtained from the National Aged Care Data Clearinghouse. Age standardisation was used to control for changes in the age and size of the Australian population. Annual age-standardised rates of admissions (subtracting transfers) and exits to the community were calculated. Linear regression models tested for a sustained increase or decrease in age-standardised rates nationally and within state and age subgroups.

Results. Notwithstanding year-to-year variation, neither admissions (subtracting transfers) nor exits to the community showed statistically significant increasing or decreasing trends in the national age-standardised rates. Admission rates varied by age and state.

Conclusions. Many more young people are admitted to PRAC each year than return to community living, with no sustained change between 2008 and 2018 at the national level. Age standardisation is crucial for evaluating systemic population-level change regarding younger people in PRAC.

What is known about the topic? As at June 2018, over 6000 people aged <65 years still live in PRAC in Australia. Previous research has demonstrated that this cohort experiences a much poorer quality of life on average than people of similar age and disability who reside in other community settings. Various strategies for improving outcomes have been trialled, many aiming to reduce the number of younger people living in aged care; the National Disability Insurance Scheme (NDIS) also has this among its aims.

What does this paper add? This paper reports trends in the number of young people entering and exiting aged care, after statistically controlling for changes due to population growth and aging. The paper highlights that national admission rates did not increase or decrease in a sustained manner, and that most of those admitted never return to community living before turning 65 years of age.

What are the implications for practitioners? Programs and policies aimed at reducing the number of young people in aged care must grapple with the scale of the issue and its apparent resistance to amelioration over the past 10 years. The results of this study provide a benchmark against which to judge the future impact of the NDIS.

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Introduction

Research as early as 1995 highlighted the substantial number of young people living in Australian aged care and their typically poor quality of life.[1–3] Since 2000, the number of people aged <65 years in permanent residential aged care (PRAC) has consistently exceeded 5900.[4] Although most of these people are aged 50–64 years, the age range is broad and the cohort consistently includes people in their 20s.

People aged <65 years have never been the target cohort for PRAC under the *Aged Care Act 1997* (Cth), but they are not

deemed ineligible merely on account of age. Government policy takes the position that some younger individuals with high care needs may 'require' PRAC as the only available option for given difficult circumstances.[5] Although individuals (or their families or guardians) may give formal consent, numerous cases have been found where individuals feel they have been essentially forced into PRAC through a lack of access to disability services or affordable and accessible housing.[6,7] This is concerning because there is evidence that, for at least some younger people in PRAC, alternative models of housing and care are feasible and greatly improve subjective well-being and social participation.[8–13]

Over the past decade, several initiatives have sought to reduce the number of younger people in PRAC, and have built a body of evidence on how this may be achieved.[14–16] Moreover, as a result of the *National Disability Insurance Scheme Act 2013* (Cth), the National Disability Insurance Scheme (NDIS) was phased into operation from 2015 to 2019. This entitles people under 65 years of age with a disability to funding for individualised disability services and 'specialist disability accommodation'.

Given the ongoing efforts to reduce the number of young people in PRAC,[17] it is essential to investigate whether the numbers have meaningfully changed over the past decade. Targets and trends have typically been discussed in terms of the total number of younger people living in PRAC.[17,18] However, changes in this number are confounded by both mortality within the cohort and people aging out of the cohort. Therefore, the present study focuses on admissions and exits to community as the variables most relevant to policy.

On the one hand, one may expect change in admissions and exits to community on account of efforts aimed at the problem; alternatively, one could also expect increases merely on account of population growth and aging. To address this, the present study analysed the 10-year trends, controlling for changes in the age distribution of the population. Direct age standardisation was conducted using the full estimated residential population (ERP) as the denominator. To the best of the authors' knowledge, age standardisation of this aged care data has not been examined previously.

Methods

Data sources

The Australian Institute of Health and Welfare (AIHW) provided three extracts from the National Aged Care Data Clearinghouse database[19,20] covering the 2007–08 to 2017–18 financial years: one set recording admissions, one set recording separations and another set recording enrolment in PRAC as at 30 June of that year. Each comprised counts disaggregated by age, state and financial year.

Where possible, assumptions about data quality were tested, and it was concluded these data were suitable for time series analysis (see File S1, available as Supplementary Material to this paper). The most recent ERP releases from the Australian Bureau of Statistics (ABS) were used for the calculation of age-specific rates in the general population.[21] Both the AIHW and ABS datasets used in this study were provided in deidentified form, without any link to individuals' personal information. Therefore, ethics approval was not required for further analysis of these data.

Measures

Admissions (subtracting transfers)

Because admissions are recorded by PRAC service providers, admission counts ordinarily include transfers of people between PRAC facilities; over the period, a mean ($\pm$ s.d.) of $13.2 \pm 2.3\%$ of national admissions per year were of this kind. To more closely reflect admissions into the PRAC system, the number of 'exits to other residential aged care' were subtracted from admissions within each cross-classification. Therefore, hereafter 'admissions' refers to admissions after subtracting transfers. This adjustment assumes that for every 'exit to other residential aged care' there is a concomitant admission to PRAC in the same year. At the state level, it is possible that some transfers occurred across state boundaries, and this represents a limitation for state-level analyses (but see File S1, 'Transfers between PRAC services'). 'Admissions' also includes readmissions of people who had previously exited to community, hospital or 'other', as well as new admissions to PRAC.

Enrolments as at 30 June

The counts of people enrolled in permanent RAC were used as provided by the AIHW.

Separations

The four remaining categories of separations were used as provided by the AIHW, namely 'exits to community', 'exits to hospital', 'deaths' and 'other exits'.

Aging out

Given the congruence of the data (see File S1, 'Congruency'), the number of people turning 65 years of age was calculated as the remaining change in enrolments after accounting for admissions and separations.

Estimated residential population

The ERP for each Age by State by Year group was obtained from the ABS; these figures estimate the number of usual residents as at 30 June each year.

Analysis

'Direct' age-standardisation[22–24] was used to aggregate the time series across age groups. Age-standardised estimates were derived by calculating age-specific rates (by 5-year age groups) and weighting them using the age distribution of a standard population. The 2001 ERP was used as the standard population, as recommended by the ABS.[25] Both admissions and exits to the community were standardised against this general population.

Although count data typically follow a Poisson or related distribution, the normal distribution provides a good approximation when events per cell exceed 10.[26] Therefore, in the present study, 10-year trends were evaluated by linear ordinary least squares regression. Each regression equation modelled an aged-standardised population rate (expressed as events per 100 000 ERP). 'Year' was treated as an interval variable, with 2008 coded as 0 and 2018 coded as 10.

When modelling disaggregated rates, to achieve 10 events per cell, rates for the jurisdictions that in 2018 contained less than

Table 1. Permanent residents of residential aged care, aged 0–64 years, and components of change

	Year (ending 30 June)										
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Admissions minus transfers	2073	2113	2162	2147	2122	2370	2495	2261	2344	2301	2187
Separations											
Exit by death	892	962	925	984	973	1007	1062	977	985	1041	1048
Exit to community	168	192	175	168	163	160	200	222	199	184	198
Exit to hospital	109	98	120	66	99	88	96	98	119	93	80
Exit to 'other'	152	170	180	217	201	229	199	149	152	118	136
Aging out	N/A	799	785	817	876	867	865	841	893	872	919
Admissions minus (separations + aging out)	N/A	−108	−23	−105	−190	19	73	−26	−4	−7	−194
Enrolments (at 30 June)	6613	6505	6482	6377	6187	6206	6279	6253	6249	6242	6048

10% of the population under 65 years of age (Northern Territory, Australian Capital Territory, Tasmania and South Australia) were pooled. Age groups were also pooled for the same reason, leading to three brackets (0–49, 50–59, 60–64 years) for admissions and two brackets (0–59, 60–64 years) for exits to the community. Pooling of states and age groups used the same age-standardisation procedures already described. To control Type 1 error rates, three models were hierarchically compared: an Age only model, a State × Age model and a full interaction model (State × Age × Year). Robustness of regression results was checked by replicating each linear model using iterated reweighted least squares fitting.[27] No meaningful differences were found, and therefore these are not reported in this paper.

Where appropriate, data are presented as the mean ± s.d.

Results

Table 1 presents the time series of simple counts of admissions, separations and enrolments. It is seen that in eight of the 10 years the number of people leaving the cohort exceeded new admissions, such that enrolments fell. As a result, there were 565 (8.5%) fewer people in the cohort at 30 June 2018 compared with 30 June 2008. However, exits to community consistently accounted for less than 10% of annual turnover (mean 8.1 ± 0.8%); 80.2% ± 1.5% of annual turnover was accounted for by deaths and aging out.

Over the period, there were 2250.2 ± 126.3 admissions per year and 186.1 ± 19.7 exits to community per year. Thus, for every one person who returned to community living over the period, a mean of 12.3 ± 1.2 were newly admitted.

In every year analysed, for all PRAC variables, counts were consistently skewed greatly towards older age groups, such that the 50–64 years subgroup accounted for the great majority of admissions, enrolments and exits. Meanwhile, the size and age distribution of the general population (the ERP) changed over the same period. Fig. 1 shows the age distributions for each variable, comparing 2008 with 2018, and demonstrates that trends apparent in the crude counts of admissions and exits are likely confounded with population change. Age standardisation is therefore required.

Age-standardised rates

Admissions

Fig. 2 presents the national age-standardised rates for admissions. It can be seen that, in age-standardised terms, the admission rate had periods of both decrease and increase; rates were at their highest in 2014 (10.52) and lowest in 2018 (8.65). However, by simple regression ($y = bx + c$), the linear trend for the period was not statistically significant ($b = -0.06$; 95% confidence interval (CI) −0.15, 0.04; $t(9) = -1.196$; $P = 0.262$).

Multiple hierarchical regression modelled age-standardised admission rates by age and state, and tested for possible linear trends within subgroups that may be obscured in the national aggregation. The Age only model was significant and explained over 90% of the variance in admissions ($F_{2,162} = 3290.00$, $P < 0.001$, adjusted $R^2 = 0.98$, Akaike information criterion (AIC) = 1056.23).

The Age × State model was also significant ($F_{14,150} = 914.20$, $P < 0.001$, adjusted $R^2 = 0.99$, AIC = 959.87). Moreover, it explained a significant additional 1% variance in comparison with the Age only model ($F_{\text{change}12,150} = 13.89$, $P < 0.001$).

The full interaction model (Age × State × Year) was also significant ($F_{29,135} = 457.40$, $P < 0.001$, adjusted $R^2 = 0.99$, AIC = 966.85). However, compared with the Age × State model, there was no significant additional variance explained ($F_{\text{change}15,135} = 1.35$, $P = 0.183$). Therefore, the Age × State model was selected as the most parsimonious. Table 2 presents the parameter estimates and standard errors for each term of this model. Table 3 presents the predicted age-standardised admission rate for each Age × State combination, as derived from this model. It is seen that, in every geographic group, admission rates increase with age, notwithstanding some variation between states.

Exits to community

Fig. 3 presents the national age-standardised rates for exits to community. It can be seen that, like admissions, the exit to community rate has had periods of both decrease and increase; the rate was at its highest in 2015 (0.95) and lowest in 2013 (0.69). However, by simple regression, the linear trend for the period was not statistically significant ($b = -0.001$; 95% CI −0.015, 0.015; $t(9) = -0.021$; $P = 0.983$).

It was originally planned to model rates of exit to community by Age, State and Year, paralleling the analyses for admissions. However, given the very small numbers of people who exit to community each year, the counts per cell were sparse, making it inappropriate to adopt a normal approximation approach. Therefore, no attempt was made to model trends within subgroups for this variable.

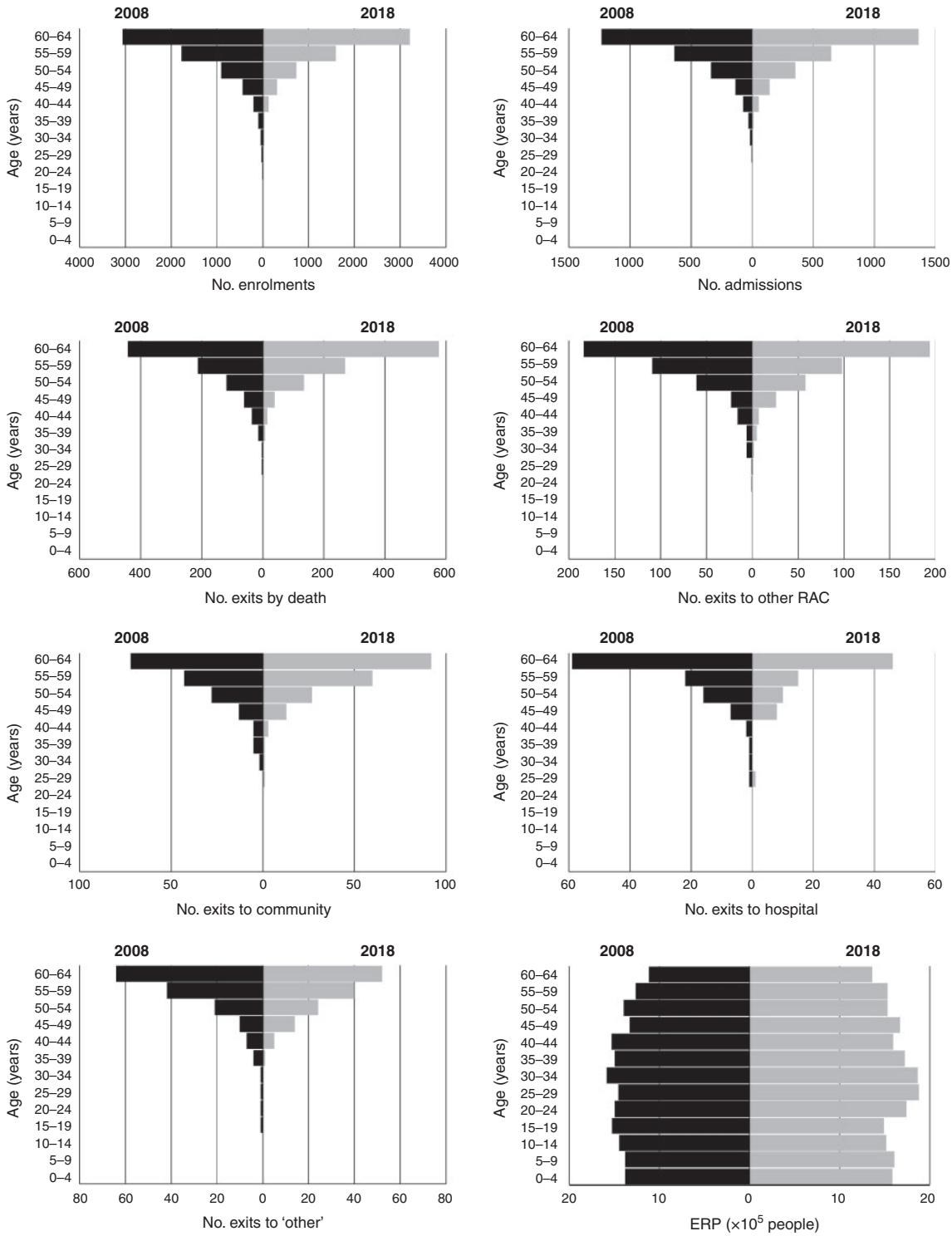

Fig. 1. Population pyramids, for people aged 0–64 years, comparing the age distribution for each variable in 2008 and 2018. ERP, estimated resident population.

Discussion

The number of younger people entering and leaving PRAC in Australia would be expected to change over time merely on account of population growth and aging. The present study shows that, after controlling for changes in population and age distribution, at the national level neither rates of admission nor rates of exit to community show statistically significant evidence of a sustained increase or decrease between 2007 and

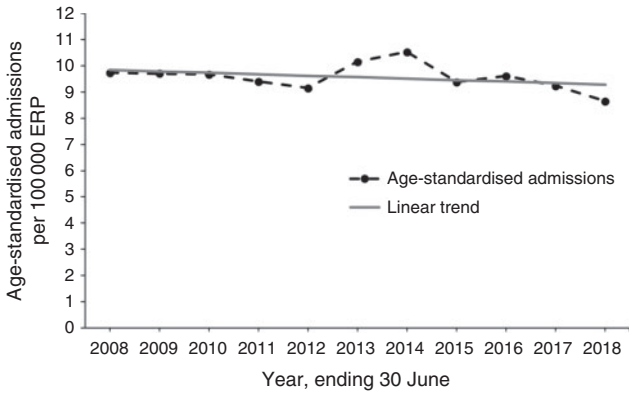

Fig. 2. Age-standardised admissions per 100 000 estimated resident population (ERP). Age-standardised admissions were calculated by subtracting transfers ('exits to other residential aged care') from the yearly admissions. The linear trend represents a simple regression ($y = bx + c$), which was not statistically significant for these data ($b = -0.06$; 95% confidence interval -0.15, 0.04; $t(9) = -1.196$; $P = 0.262$).

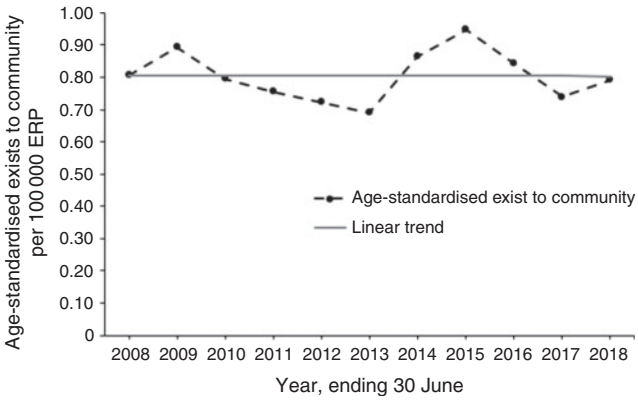

Fig. 3. Age-standardised exits to community per 100 000 estimated resident population (ERP). The linear trend represents a simple regression ($y = bx + c$), which was not statistically significant for these data ($b = -0.001$; 95% confidence interval-0.015, 0.015; $t(9) = -0.021$, $P = 0.983$).

Table 2. Parameter estimates for Age × State regression model of age-standardised admissions

Note, State:New South Wales and Age:60–64 years are the reference groups represented by the intercept term. Vic., Victoria; Qld, Queensland; WA, Western Australia

Term	Parameter estimate	s.e.	*P*-value
Intercept	100.03	1.27	<0.001
Age:0–49 years	−98.38	1.80	<0.001
Age:50–59 years	−68.17	1.80	<0.001
State:Vic.	−10.87	1.80	<0.001
State:Qld	−9.83	1.80	<0.001
State:WA	−21.39	1.80	<0.001
State:Other	−9.67	1.80	<0.001
Age:0–49 years × State:Vic	10.76	2.55	<0.001
Age:0–49 years × State:Qld	9.33	2.55	<0.001
Age:0–49 years × State:WA	20.97	2.55	<0.001
Age:0–49 years × State:Other	9.60	2.55	<0.001
Age:50–59 years × State:Vic	8.33	2.55	<0.01
Age:50–59 years × State:Qld	4.56	2.55	
Age:50–59 years × State:WA	14.02	2.55	<0.001
Age:50–59 years × State:Other	5.99	2.55	<0.05

Table 3. Predicted age-standardised admission rate (per 100 000 estimated resident population) by age and state

NSW, New South Wales; WA, Western Australia

Age (years)	State or territory				
	NSW	Victoria	Queensland	WA	Other
0–49	1.65	1.54	1.14	1.23	1.58
50–59	31.86	29.32	26.58	24.49	28.19
60–64	100.03	89.16	90.19	78.64	90.36

2018. Today, as it was a decade ago, many more people under 65 years of age enter PRAC than return to community living. However, the total number of younger people in PRAC has not increased due to the effects of mortality and aging out.

This is not to say that rates were static or that initiatives and reforms did not have an impact, but that, overall, decreases in some years were offset by increases in others. It is worth noting the observed decrease in age-standardised admissions between 2009 and 2012. This reduction over 4 years loosely corresponds to the intake period of the A$244 million Young People in Residential Aged Care (YPIRAC) program, a Council of Australian Governments (COAG) initiative that aimed to reduce the number of younger people in PRAC over 5 years by 425–689 people.[18] Although the present study cannot establish cause and effect, the COAG program is a plausible explanation for this short-term reduction in admissions.[18,28]

Despite the decrease from 2009 to 2012, in the following 2 years (2012–14) the admission rate increased sharply and exceeded the 2009 rate, effectively offsetting the earlier reductions. Although it may have been expected that the conclusion of the COAG program would see rates return to previous (age-standardised) levels, the reasons underlying a further increase in admissions is unclear. One possibility is that there were 2–3 years of anticipation between the Productivity Commission recommending an NDIS in 2011[29] and the implementation of the first NDIS trial sites in 2015.[30] Preparation for NDIS may have meant that development of disability services and accommodation slowed in expectation of better opportunities arising under the NDIS.

Although the NDIS was phased into full geographical coverage between 2015 and 2019, one would not necessarily expect to see a marked change in admission and exit rates immediately reflected. In addition to the time involved in assessing eligibility and individual funding plans for NDIS participants, participants may need considerable time to arrange suitable housing and services. Moreover, despite the availability of funding, there remains a considerable undersupply of disability services, and in particular specialist disability accommodation.[1,17,31,32] This notwithstanding, the present study shows that the age-standardised admission rate for 2018 was an 11-year low. This low rate may be the first sign of an effect of the NDIS, but it remains to be seen whether it will be sustained or reduce further in subsequent years. Only sustained reductions would provide

evidence of effective systemic change that will scale with population growth. As for exits to community, recent NDIS statistics imply young people in PRAC have only recently joined the scheme, with 881 NDIS participants as at 31 March 2017, rising to 4093 participants as at 31 March 2019.[33] Therefore, there was not sufficient time by the final data point of our time series (year ending 30 June 2018) for most of these participants to achieve exit to community.

Regarding differences in admission rates within Age and State, time trends within subgroups were not of sufficient magnitude to reach statistical significance. The average differences between jurisdictions in admission rates may relate to differences in policies and systems, as well as to how people are distributed between metropolitan, regional and remote areas and patterns of inter- and intrastate migration (of people with disability vs those without). Therefore, although state and territory rates may be used as benchmarks for the corresponding state and territory, it is not necessarily appropriate to benchmark states and territories against each other.

The results of the present study highlight that, with PRAC being so strongly correlated with age, age-standardisation is essential for drawing meaningful comparisons over time. The present study used the ERP as a denominator on which to age standardise. This has the advantage of being a reliable, clearly defined statistic that can be obtained each year to easily update these time series. Its use reflects the logic that all individuals have a chance of acquiring severe disability before the age of 65 years, and therefore a chance of entering PRAC. Moreover, it controls for population growth and aging without introducing confounding variance from shifting definitions of different target subpopulations. We suggest that linear trend analysis provides a useful way to detect sustained long-term change in these rates.

Naturally, there are limitations to what can be inferred from these time series. This occurs because data are recorded by the aged care provider in high-level categories that do not capture some relevant context. For example, exits to community likely include instances where someone with a terminal illness chooses to return home to die; they may also include instances where someone briefly returns to community but is then readmitted to the same, or a different, aged care facility. More generally, admission and exit rates do not directly speak to the quality of life experienced by younger people in PRAC, those who leave PRAC or those who avoid admission in the first place. For example, admission counts may be reduced on paper by shifting responsibility to hospitals or restricting access to PRAC, but this would not necessarily represent a better quality of life for individuals with high support needs.

Conclusion

The present findings provide a basis for understanding the magnitude of the issue regarding younger people in PRAC and raise questions about what constitute reasonable targets for the future. Progress may depend on further research into the pathways, care needs and life expectancies of younger people in PRAC, and policy clarity on which systems (health, disability or aged care) are expected to take responsibility for which cohorts. Whatever the way forward, progress should be tracked in terms of age-standardised rates of admission and exit to community and whether sustained reduction is achieved in the long term.

Competing interests

There are no competing interests for any of the authors.

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