

Chapter 2

Young people in residential care and unmet need—trends and statistics

Introduction

- 2.1 This chapter discusses the following terms of reference:
- (a) The estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care; and
 - (b) Short- and long-term trends in relation to the number of young people being cared for within the aged care system.

Young people living in the residential aged care system and other cared accommodation

2.2 In the context of this inquiry, young people are defined as those under 65 years of age. The young people referred to in this inquiry are most likely subject to severe or profound core activity limitation. A person may experience a severe or profound core limitation if they require assistance (sometimes or always) with self-care, mobility and communication. In addition to these core activity limitations, a person with disability may experience obstacles to participation in education, employment, and social or recreational opportunities. These are referred to as participation restrictions.¹

2.3 The disabilities that these young people present with are generally the 'result of catastrophic injury or through progressive [and degenerative] neurological diseases', with most of these people 'categorised as high dependency enter[ing] residential aged care on discharge from hospital'.² Examples of catastrophic injury include acquired brain injury (ABI) and traumatic brain injury (TBI). Progressive and degenerative neurological diseases include multiple sclerosis, neuromuscular disorders (such as muscular dystrophy), motor neurone disease, Huntington's disease and

1 Australian Institute of Health and Welfare, *Young Australians: their health and wellbeing 2011*. 2011. Cat. no. PHE 140. Canberra, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737419259> (accessed 20 January 2015).

See also: ABS 4430.0, Glossary. <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4430.0Glossary602012?opendocument&tabname=Notes&prodno=4430.0&issue=2012&num=&view=> (accessed 22 January 2015).

2 Young People in Nursing Homes—National Alliance, Our Members. <http://www.ypinh.org.au/about/our-members> (accessed 21 January 2015).

Parkinson's disease.³ Those with intellectual disabilities such as Down Syndrome or severe autism may find themselves in a RACF not as a result of their disability, but due to the advanced ageing or death of parent carers.⁴

Aged care

2.4 The committee notes that aged care facilities are designed for those aged over the age of 65 years and that there are a range of age-appropriate supports for those aged over 65 living in these facilities. However, evidence to the committee throughout this inquiry has shown this is not the case for those under 65.

2.5 Young Australians under the age of 65 currently occupy 5 per cent of residential aged care facility (RACF) beds. This is primarily because the current disability system cannot provide appropriate supports and services for these young people.⁵

2.6 The Productivity Commission's Report on Government Services states that in 2013–14 there were 7 183 young people living in residential aged care (YPIRAC) facilities across Australia, with the vast majority of these people living in NSW, followed by Victoria and Queensland. Nearly 90 per cent of these people were aged between 50–64 years.⁶ This data can be seen below in Table 2.1. A more comprehensive breakdown of young people by age cohort can be seen below in Table 2.2.⁷

3 Young People in Nursing Homes, *Submission 93*, pp 36–37. See also: Australian Huntington's Disease Association, *Submission 79*; Multiple Sclerosis Ltd, *Submission 65*; Parkinson's Western Australia, *Submission 101*.

4 Down Syndrome Victoria, *Submission 48*, p. 1.

5 Young People in Nursing Homes—National Alliance, Our Members. <http://www.ypinh.org.au/about/our-members> (accessed 21 January 2015).

6 Australian Government Productivity Commission, *Report on Government Services 2015*, p. 417, <http://www.pc.gov.au/research/recurring/report-on-government-services/2015/community-services/services-for-people-with-disability/rogs-2015-volume-f-chapter14.pdf> (accessed 15 February 2015). See also: *Australian Institute of Health and Welfare*, *Submission 141*, p. [5].

7 *Australian Institute of Health and Welfare*, *Submission 141*, p. [5].

Table 2.1: Number of young people (<65 years of age) in residential aged care facilities by state and age group in 2013–14

	Unit	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
2013-14										
Non-Indigenous										
0-49 years	no.	244	172	119	33	<60	10	np	np	636
50-64 years	no.	2 343	1 657	1 191	481	507	193	<70	10	6 451
Indigenous										
0-49 years	no.	28	7	30	26	np	–	–	<5	96
Total	no.	2 615	1 836	1 340	540	565	203	78	15	7 183

Source: Australian Government Productivity Commission, *Report on Government Services 2015*, Table 14A.68.

Table 2.2: Number and per cent of young people in permanent residential aged care by age group in 2013–14

Age group	Number of young people in care	Per cent of total
<20	2	0.03
20–24	13	0.18
25–29	22	0.31
30–34	36	0.50
35–39	60	0.83
40–44	190	2.64
45–49	404	5.62
50–54	891	12.39
55–59	1 867	25.95
60–64	3 709	51.56
TOTAL <65	7 194	100.00

Source: Australian Institute of Health and Welfare, *Submission 141*, p. [5].

2.7 The committee notes that the committee has received evidence suggesting a wide range of statistics and is concerned that these statistics appear to be unreliable, and may in fact be understated. Most submissions agreed that there are currently between 6000 to 7000 young people living in aged care, the committee has received

evidence suggesting that these numbers could be higher.⁸ Aged and Community Services argues in its submission that between 2008–09 and 2013–14, the number of young people in aged care have increased from 7 755 to 8 658.⁹

2.8 Further to this, there is confusion in some states as to the age at which it is considered inappropriate for a person to live in aged care. In evidence to the committee Dr Ron Chalmers, Director General of the Western Australian Disability Services Commission (DSC) argued that Western Australia only considered those under 50 living in RACF as being inappropriately placed.

[A]t the moment we are aware of only about 50 people under the age of 49 who, we believe, are inappropriately placed...

Clearly, there are hundreds of people in that range, predominantly between 50 and 60, and the bulk of those people are there for medical reasons—again, I come back to say I talk from a Disability Services perspective—but the number of people who we are aware of and whom we focus on who would be eligible for disability services, either current or NDIS, is 49 [people under the age of 50] at the moment.¹⁰

The committee notes its concern that the Director General of the DSC does not deem the 50–64 year cohort as being inappropriately placed in RACF or consider that they require a specific focus. It is the committee's view that it is the 50–64 year cohort—who make up nearly 90 per cent of all young people living in RACF—that require urgent attention.

Cared Accommodation

2.9 It is important to note that this inquiry is not limited to those young people in aged care; it also includes young people living in other congregate or institutional care. In their submission, the Australian Bureau of Statistics stated that in 2012 there are 11 000 people, aged 64 years or less, with severe or profound core-activity limitation living in cared accommodation.¹¹ Cared accommodation is defined as hospitals, nursing homes, hostels and other homes with six or more people.¹² As such,

8 Summer Foundation, *Submission 109*, pp 25–32; Young People in Nursing Homes, *Submission 93*, p. 47. See also: Australian Government Productivity Commission, *Report on Government Services 2015*, p. 417, <http://www.pc.gov.au/research/recurring/report-on-government-services/2015/community-services/services-for-people-with-disability/rogs-2015-volume-f-chapter14.pdf> (accessed 15 February 2015).

9 Aged and Community Services Australia, *Submission 73*, p.4.

10 Dr Ron Chalmers, Director General, Western Australia Disability Services Commission, *Committee Hansard*, Perth, 17 February 2015, p. 32.

11 Australian Bureau of Statistics, *Submission 77a*, p. 4.

12 Australian Bureau of Statistics, *4430—Disability, Ageing and carers, Australia: Summary of Findings, 2012: Explanatory Notes*, November 2013, <http://www.abs.gov.au/Ausstats/abs@.nsf/Latestproducts/4430.0Explanatory%20Notes5002012?opendocument&tabname=Notes&prodno=4430.0&issue=2012&num=&view=> (accessed 4 June 2015).

taking into account that there are approximately 7 000 in aged care, there are nearly 3 000 people living in some form of congregate or institutional care.

Trends for young people

2.10 The total numbers of young people living in RACF has fluctuated from a low of 6 451 in 1997–98 to a peak of 7 516 in 2007–08. Between 1997–98 and 2013–14, young people living in RACF decreased from 19 to 2 for those aged under 20 years; from 118 to 37 for those aged under 30 years; from 1 358 to 727 for those aged under 50 years. These represent decreases in numbers in aged care by 950, 318 and 186 per cent respectively. For those aged 50–64, there was an increase from 5 093 to 6 487 for young people living in aged care; and from 2 686 to 3 709 for those aged 60–64. These represented increases of 127 and 138 per cent respectively.¹³

2.11 It is clear from these statistics that there are two distinct groups of young people that receive different service responses resulting in different accommodation and support options. There are those under the age of 50, where numbers are decreasing, and there are those aged 50–64 where numbers are increasing.

2.12 There are two key trends behind these statistics, one is numbers of people being admitted to RACF and the other is numbers of those returning to live in the community within these two age cohorts. Between 2006–07 and 2013–14, there has been a decrease of 0.9 per cent of admissions into RACF for those aged 0–49 years; this compares to a 26.3 per cent increase for those aged 50–64 years during the same period. There has been a 16 per cent increase in the numbers of young people leaving RACF to return to live in their own home or with family (aged 0–49). Conversely, for those aged between 50–64 years, there has been a 6.3 per cent increase in the numbers of young people moving from the community into RACF.¹⁴

2.13 There have been a range of different experiences between the states and territories during the period 2006–07 and 2013–14. For those under the age of 49 years, Tasmania and the NT had less than five people in RACF, whilst the ACT records none. Queensland recorded a 33 per cent fall. The states with larger populations registered small increases. The general trend for this age group was either down or small increases. For the 50–64 years age group during the same time period, nearly all states except the ACT—where numbers decreased by 25 per cent—registered an increase in numbers living in RACF. Tasmania recorded the greatest percentage increase (80 per cent), although this started from a small base. The greatest

13 Australian Institute of Health and Welfare, *Submission 41*, p. [5].

14 Australian Government Productivity Commission, *Report on Government Services 2015*, p. 417, <http://www.pc.gov.au/research/recurring/report-on-government-services/2015/community-services/services-for-people-with-disability/rogs-2015-volume-f-chapter14.pdf> (accessed 15 February 2015).

increase in absolute numbers occurred in the most populous states—NSW, Victoria and Queensland.¹⁵

Recent initiatives and inquiries for young people with disability in RACF¹⁶

2.14 In 2005, the Senate held an inquiry into *Quality and equity in aged care*, with Chapter 4 addressing the issue of young people in RACF. Recommendation 22 of that report states:

The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most instances. The Committee therefore recommends that all jurisdictions work cooperatively to:

- assess the suitability of the location of each young person currently living in aged care facilities;
- provide alternative accommodation for young people who are currently accommodated in aged care facilities; and
- ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options.¹⁷

2.15 In response, the Council of Australian Governments (COAG) agreed to a five year initiative—Younger People with Disability in Residential Aged Care (YPIRAC)—in February 2006. The YPIRAC program has been the key driver behind the fall in numbers for the 0–49 year cohort.¹⁸ This five year Council of Australian Government (COAG) initiative operated from 2006 until 2011. The main objectives of YPIRAC were:

- i) People moving out of residential aged care to more age-appropriate supported disability accommodation
- ii) People at risk diverted from inappropriate admission to residential aged care

15 Australian Government Productivity Commission, *Report on Government Services 2015*, p. 417, <http://www.pc.gov.au/research/recurring/report-on-government-services/2015/community-services/services-for-people-with-disability/rogs-2015-volume-f-chapter14.pdf> (accessed 15 February 2015). See also: Tasmanian Government, *Submission 118*; Brightwater Care Group, *Submission 115*, pp 2–4.

16 See also: *Submission 55*, pp 4–5.

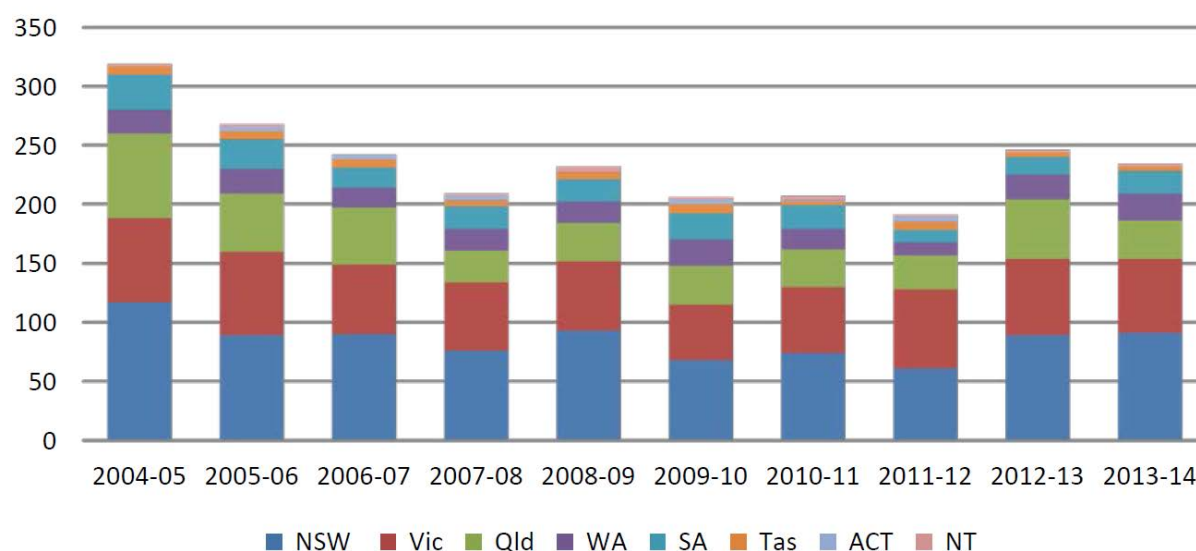
17 Senate Community Affairs References Committee, *Quality and equity in aged care*, June 2005, p. 127, http://www.aph.gov.au/~media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/aged_care04/report/report_pdf.ashx (accessed 22 January 2015).

18 Department of Social Services, *Submission 55*, pp 7–8. It is clear that the precipitous fall in numbers for those aged under 30 years of age has been driven by this program.

- iii) People provided with enhanced services within a residential aged care setting, for whom residential aged care is the only available, suitable supported accommodation option.¹⁹

Despite making up a much lower proportion of the total in aged care, the primary beneficiaries of the YPIRAC program have been the 0–49 year cohort. There has been no sustained push for those aged 50–64 years to be moved into the community. This trend is illustrated in Figure 2.1, where a sustained fall in numbers of people (aged 0–49 years) admitted to residential aged care falls during the years when the YPIRAC program is operating (2006–2011), with increases in admissions from the programs end. The YPIRAC program will be discussed in more detail in Chapter 5.

Figure 2.1: Number of people (aged 0–49 years) admitted to permanent residential aged care



Source: Department of Social Services, *Submission 55*, p. 7.

2.16 On 1 January 2009, the National Disability Agreement (NDA) replaced YPIRAC and the Commonwealth State and Territory Disability Agreement. However, the YPIRAC targets remained in place and were assessed in the final report for the YPIRAC initiative:

Over the five years of YPIRAC to 2010–11, an estimated 1,432 received services from the YPIRAC initiative. Of these, an estimated 250 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation); 244 people achieved the second YPIRAC objective (diversion from residential aged care); and 456 people achieved the third YPIRAC objective (receiving enhanced services within residential aged care, when this was the only available, suitable accommodation option).

19 Australian Institute of Health and Welfare, *Younger people with disability in residential aged care 2010–11*. 2012. Bulletin no. 103. Cat. no. AUS 155. Canberra, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421563> (accessed 22 January 2015).

Over the life of the YPIRAC initiative, the total number of permanent residents of residential aged care under 65 has generally decreased and, in particular, there has been a 35% drop in the number of persons under 50 living in permanent aged care since 2005–06.²⁰

2.17 However, in 2011, a joint study conducted by the Summer Foundation and Monash University assessed that the first four years of the YPIRAC program had not met its objectives. The study found:

[T]he development of new accommodation options has been slow. The 5-year program aims to move 689 young people out of nursing homes; in the first 4 years of the initiative 139 people had been moved out.

However, the study also noted that 'the lives of those who have been helped by the program have been enormously improved'. The report concluded with the following observation:

The accommodation options currently being developed for this target group will soon be at capacity. Without sustained investment in developing alternative accommodation options and resources to implement systemic change [approximately] 250 people under 50 are likely to continue to be admitted to aged care each year.²¹

2.18 In 2014, the Senate held an inquiry into *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia*, with Chapter 7 examining the issue of younger onset dementia. Recommendation 17 of this report states:

The committee recommends that a review of the adequacy of respite facilities for Younger Onset Dementia patients be carried out urgently.

Recommendation 18 states:

The committee recommends that the Commonwealth fund the development of a pilot Younger Onset Dementia specific respite facility at either the Barwon or Hunter area National Disability Insurance Scheme trial sites.²²

2.19 The YPIRAC initiative and the NDA will be discussed in more detail in Chapter 5.

20 Australian Institute of Health and Welfare, *Younger people with disability in residential aged care 2010–11*. 2012. Bulletin no. 103. Cat. no. AUS 155. Canberra, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421563> (accessed 22 January 2015).

21 Dianne Winkler, Louise Farnsworth, Sue Sloan, Ted Brown, 'Young People in aged care: progress of the current national program', *Australian Health Review*, vol. 35, pp 320–326.

22 Senate Community Affairs References Committee, *Care and management of younger and older Australian living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, March 2014, p. xi, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Dementia/Report/~media/Committees/Senate/committee/clac_ctte/dementia/report/report.pdf (accessed 3 February 2015).

Unmet need

2.20 In addition to quantifying the number of those young people who currently live in residential care and those who are transitioning, it is also important to quantify the level of unmet need. That is, those individuals living in the community who require further assistance now or in the future.

2.21 As discussed earlier in this chapter, this inquiry is focused on those with a severe or profound core activity limitation. According to the Australian Bureau of Statistics, there are:

[A]pproximately 440,700 people with severe or profound disability under the age of 65 and who are not in cared-accommodation who have a need for formal assistance (such as from a nurse, a Government service, a housekeeper, etc). Around 280,500 of these people with a need for formal assistance report that their need was unmet.²³

2.22 Clearly these statistics do not differentiate between those who require access to support services and those requiring accommodation. However, a 2005 report by the Australian Institute of Health and Welfare (AIHW) found that for people with severe and profound core activity limitation 'unmet demand for accommodation and respite services was estimated at 23 800 people [and] for community access services at 3 700'. The AIHW classified unmet demand as the total of undermet demand and unmet demand.²⁴

2.23 The committee received evidence from Ms Taryn Harvey, CEO of Developmental Disability WA about unmet need being as much about those who indicate a need for a planned transition as those who are currently not having their needs met. Ms Harvey spoke specifically about the group of young people with 'significant intellectual disabilities who are [currently] living at home with [ageing] parents' and will need to plan for the day when their parents are unable to care for them any longer:

One of the priorities for us in working on supporting the NDIS is how we will negotiate the concept of 'reasonable and necessary' and how that will intersect with the expectations of individuals and families around making planned transitions out of the family home: what does 'reasonable and necessary' mean when people are anticipating wanting to make a planned transition as opposed to reinforcing the existing system that we have via CAP [Combined Application Process], where people are actually not making transitions until the system deems that it is necessary?²⁵

23 Australian Bureau of Statistics, *Submission 77*, p. 3.

24 Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, 2007, pp 1–2, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=644245539> (accessed 8 April 2015). Undermet demand is when services are not providing enough hours or costing too much and hence not being utilised as required

25 *Committee Hansard*, Perth, 17 February 2015, p. 23.

2.24 In its submission, Children with Disability Australia suggests that 'identifying the number of young people who require high levels of care and who are at risk of entering into the aged care system is complex'. The Australian Bureau of Statistics notes that there are currently 11 300 primary carers aged over 65 years of age caring for someone with a severe or profound disability; there are over 40 000 primary carers aged 50–64 years.²⁶ Although this data is valuable there is a need for more comprehensive data detailing current and future needs. It is unclear how many of these young people will be accommodated in residential care facilities as their parents age and their capacity to fulfil their caring duties decreases.

2.25 Some partners, families and friends manage to care for their young disabled through sheer courage and determination with little support from government and service providers. In most cases, it is the unexpected crisis that can upset this delicate equilibrium. The crisis point can manifest in many forms but will likely relate to the health of the carer, other caring or employment responsibilities (including other children), an increase in the level of care required due to deterioration of the care receiver's health, financial stress, and mental and physical exhaustion after a long period of caring with no respite.²⁷ The importance of carer respite in the context of maintaining family units will be discussed in Chapter 3.

26 Answer to Question on Notice, Australian Bureau of Statistics, 3 June 2015, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents, (accessed 4 June 2015).

27 Children with Disability Australia, *Submission 102*, p. 8. See also: Focus ACT, *Submission 45*, pp 3–4.