

The Senate

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Community Affairs  
References Committee

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Adequacy of existing residential care  
arrangements available for young people  
with severe physical, mental or intellectual  
disabilities in Australia

June 2015

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## **ABBREVIATIONS**

AA	Alzheimer's Australia
ABI	Acquired Brain Injury
ACAT	Aged Care Assessment Team
ACT	Australian Capital Territory
ADACAS	Australian Capital Territory Disability, Aged and Carer Advocacy Service Inc
AHAC	Anyinginyi Health Aboriginal Corporation
AHCS	Australian Home Care Services
AIHW	Australian Institute of Health and Welfare
BCG	Brightwater Care Group
CAP	Combined Application Process
COAG	Council of Australian Governments
DANA	Disability Advocacy Network Australia
DDWA	Developmental Disability Western Australia
DRC	Disability Reform Council (COAG)
DSC	Disability Services Commission (Western Australia)
DSS	Department of Social Services (Australian Government)
FASD	Foetal Alcohol Spectrum Disorder
HACC	Home and Community Care
HCS	Home Care Service
HOF	Housing Options Facilitator
ILC	Information, Linkages and Capacity Building
ISP	Individualised Support Package
LAC	Local Area Coordinators

LASA	Leading Age Services
LWB	Life Without Barriers
MJD	Machado Joseph Disease
NACAP	National Aged Care Advocacy Program
NADA	National Disability Advocacy Program
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
ND SPP	National Disability Specific Purpose Payment
NIIS	National Injury Insurance Scheme
NRHA	National Rural Health Alliance
NSW	New South Wales
NT	Northern Territory
OPAQ	Office of the Public Advocate Queensland
PC	Productivity Commission
PCAS	Person Centred Active Support
PwDWA	People with Disability Western Australia
QBISM	Quarterly Brain Injury Services Meeting
RACF	Residential Aged Care Facility
RN	Registered Nurse
SAIF	Supported Accommodation Innovation Fund
TAC	Transport Accident Commission (Victoria)
TBI	Traumatic Brain Injury
UNSW	University of New South Wales
WA	Western Australia

YODKW	Younger Onset Dementia Key Worker
YODKWP	Younger Onset Dementia Key Worker Program
YPINHNA	Young People in Nursing Homes—National Alliance
YPIRAC	Younger People in Residential Aged Care



# **LIST OF RECOMMENDATIONS**

## **Recommendations to the Australian Government**

### **Recommendation 1**

**6.7** The committee recommends that the Australian Government compile a database of all young people under the age of 65 years living in residential aged care facilities using the data held by the Aged Care Assessment Team (ACAT) program. This list should be provided in a regularly updated form to the National Disability Insurance Agency (NDIA) and to state and territory governments. This data should include the following information:

- name;
- age and age of entry to aged care;
- diagnosis;
- length of time spent in the aged care system; and
- the factors that need to be addressed for the person to move out of the aged care facility.

### **Recommendation 2**

**6.8** The committee recommends that the Australian Bureau of Statistics (ABS) conduct a Longitudinal Survey of Disability, Ageing and Carers in addition to its triennial survey of Disability, Ageing and Carers.

### **Recommendation 3**

**6.10** The committee recommends that the Australian Government develop and implement a comprehensive assessment and placement tool or residential assessment instrument to assess the care and accommodation needs for all young people living in or at risk of entering residential care.

### **Recommendation 4**

**6.12** The committee recommends that supplementary assessment guidelines and tools are developed for the ACAT program to ensure that all young people being considered for an aged care placement are properly assessed. As part of this process, the committee recommends that:

- all young people placed in aged care are intensively case managed; and
- all ACAT placements for those aged under 65 are reviewed on an annual basis.

## **Recommendation 5**

**6.13** The committee recommends that the accreditation standards for residential aged care are amended to include standards relating to the clinical outcomes and lifestyle needs of young people. In order to assist with meeting these new accreditation standards, the committee recommends that the Australian Government:

- provide a supplementary payment to residential aged care facilities to ensure that these accreditation standards can be met; and
- invest in disability specific training for all staff involved in the care of young people living in aged care. This training should focus on building improved awareness of the needs of young people and those living with disability in order to provide better support. It should also lead to improved connectivity between the aged care sector and other service sectors including allied health and disability services.

## **Recommendation 6**

**6.17** The committee recommends that the Department of Social Services' current discussion paper on disability housing consider capital funding options for construction of specialised disability accommodation.

**6.18** The committee recommends that the discussion paper is released as a matter of urgency.

**6.19** The committee recommends that the Australian Government establish a supported disability accommodation fund similar to the Supported Accommodation Innovation Fund.

## **Recommendations to the Joint Standing Committee on the National Disability Insurance Scheme**

### **Recommendation 7**

**6.21** The committee recommends that the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) conduct an inquiry into the issue of disability housing after the release of the discussion paper on disability housing.

## **Recommendations to the Council of Australian Governments (COAG)**

### **Recommendation 8**

**6.23** The committee recommends that the COAG develop and implement a national rehabilitation strategy including a framework for the delivery of slow stream rehabilitation in all jurisdictions.

## **Recommendation 9**

**6.28** The committee recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas:

- assign an advocate to all young people living in residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person;
- assign an advocate to all young people at risk of entering residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person. The advocate should be made available as early as possible after diagnosis of an illness or disability and be assigned before any placement commences;
- extend the National Younger Onset Dementia Key Worker Program (YODKWP) to all young people identified as being at risk of placement in residential care to provide collaborative case management. The key worker should be assigned before any placement commences; and
- these programs should be proactively extended to young people living in residential care facilities under the age of 65 years by June 2017. Consideration of the mental health status of young people should be prioritised with appropriate support provided where necessary.

## **Recommendation 10**

**6.30** The committee recommends that the NDIS, in all NDIS trial sites, should consider how it supports those with Foetal Alcohol Spectrum Disorder (FASD).

**6.31** The committee also recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas work closely with community health services to provide the following for those with FASD

- agreement on a standardised diagnostic tool; and
- provision of early intervention services and other health services such as speech pathology, physiotherapy and occupational therapy.

## **Recommendation 11**

**6.32** The committee recommends that the COAG establish a joint taskforce for young people living in residential care. This taskforce will:

- facilitate the development and implementation of integrated service pathways involving a range of portfolios at a state and federal level including housing, health, aged care, disability, and transport; and
- facilitate the collation and development of information packs outlining support, transition and placement options for young people. These packs should be made available to young people, their families, health practitioners and other relevant professionals in hospitals and aged care facilities. This process should

**collate all information and tools developed by the states during the Younger People with Disability in Residential Aged Care (YPIRAC) program and lead to the development of a standardised national information pack and make available to all state and territory governments for deployment.**

**6.33 The joint taskforce will also be responsible for oversight of the following for young people living in a Residential Aged Care Facility (RACF):**

- access to appropriate prescribed specialist services including speech pathology, physiotherapy, occupational therapy and other allied health services;**
- the national rehabilitation strategy;**
- the provision of advocates;**
- the expanded key worker program;**
- access to fully funded equipment as part of all state and territory Aids and Equipment schemes;**
- a cross sector approach is adopted to explore options for the provision of short term respite services; and**
- that all young people who indicate that they do not wish to live in residential care are transitioned into appropriate alternate accommodation by June 2018.**

#### **Recommendation 12**

**6.34 The committee recommends that the joint taskforce issues a half yearly report on the progress of Recommendation 11 to the COAG.**

# Chapter 1

## Introduction

1.1 This inquiry is concerned with young people with severe disability aged 65 years or under who currently live in or are at risk of entering a residential care facility. This includes those who live in some form of congregate or institutional care. The inquiry has provided an opportunity for young people, their families, carers, service providers, and state and federal government agencies to reflect on the policies and systems that have led to young people being placed in this situation. The committee wishes to highlight the fact that nearly 90 per cent of young people living in aged care are aged 50–64 years. It is the needs of this group that have not been adequately addressed in previous programs such as the Younger People with Disability in Residential Aged Care initiative (YPIRAC) and it is imperative that the needs of this group are front and centre of any response.

1.2 The committee notes that this inquiry is conducted at a time of transition as the National Disability Insurance Scheme (NDIS) is being phased in. The Commonwealth Government has assured the committee that the needs of this cohort will be met once the NDIS is fully rolled out across the country. The committee has a number of concerns with this approach. First, the full rollout of the NDIS is not scheduled to be completed until at least 2018. Second and most importantly, this is a discrete group of people with complex needs. The NDIS has not demonstrated that it has a methodology to provide support services and accommodation that meet the needs of these people. It is the committee's view that too much time has already been lost and that young people in residential care require a solution now to improve their lives in the interim period between the NDIS trials and full roll-out of the NDIS. This report offers a range of practical recommendations that can be utilised during this interim period to provide a dignified and just pathway forward through appropriately supporting the accommodation and other needs of these young people.

### Terms of Reference

1.3 On 3 December 2014, the Senate referred the following matters to the Senate Community Affairs References Committee for inquiry and report by 30 June 2015:

The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia, with reference to:

- (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;
- (b) short- and long-term trends in relation to the number of young people being cared for within the aged care system;
- (c) the health and support pathways available to young people with complex needs;

- (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities;
- (e) alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities;
- (f) the options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities;
- (g) what Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future;
- (h) the impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation;
- (i) state and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth's contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction; and
- (j) any related matters.<sup>1</sup>

### **Conduct of the inquiry**

1.4 Details of the inquiry were placed on the committee's website and the committee wrote to over 80 organisations, inviting submissions by 6 February 2015. Submissions continued to be submitted after that date.

1.5 The committee received 167 submissions from a diverse range of individuals and organisations including young people and their families, community service providers, aged care providers, advocacy groups, and Commonwealth, State and Territory agencies and departments. A list of the individuals and organisations who made submissions is provided at Appendix 1.

1.6 Public hearings were held throughout Australia: Perth on 17 February 2015; Sydney on 19 February 2015; Melbourne on 11 March 2015; Hobart on 12 March 2015; Darwin on 1 April 2015; and Canberra on 15 May 2015. Transcripts of the hearings are available on the committee's website, and a list of the witnesses who gave public evidence at the hearings is provided at Appendix 2.<sup>2</sup>

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1 *Journals of the Senate*, No. 73—3 December 2014, pp 1965–1966.

2 See: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care)

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1.7 The committee also conducted a site visit to the Uniting Church's Rowallan Park Intentional Community south of Hobart on 12 March 2015. This visit is discussed further in Chapter 4. The committee extends its sincere thanks to the residents of the Intentional Community for inviting the Committee and Secretariat into their homes. The committee would also like to thank Reverend Colin Gurteen, Mr Richard Romaszko, Mrs Janine Romaszko, Ms Lucia Fitzgerald and members of the Kingston Congregation.

### **Acknowledgements**

1.8 The committee acknowledges those that contributed to the inquiry through submissions or as witnesses. The committee thanks young people and their families who have shared their personal accounts as part of this inquiry.

### **Structure of the report**

1.9 The committee's report is structured in the following way:

- Chapter 2 provides the statistics and trends for young people living in residential care;
- Chapter 3 discusses the appropriateness of the residential care system for young people and issues around deinstitutionalisation;
- Chapter 4 examines current health and support pathways available to young people with complex needs, and alternative systems of care available;
- Chapter 5 discusses the National Disability Agreement, the Younger People with Disability in Residential Aged Care Initiative (YPIRAC), and the National Disability Insurance Scheme. It also considers actions taken by state governments since the conclusion of the YPIRAC program; and
- Chapter 6 presents the committee's conclusions and recommendations.



## 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.<sup>1</sup>

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'.<sup>2</sup> 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

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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.<sup>3</sup> 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.<sup>4</sup>

### *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.<sup>5</sup>

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.<sup>6</sup> 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.<sup>7</sup>

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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
<b>Total</b>	<b>no.</b>	<b>2 615</b>	<b>1 836</b>	<b>1 340</b>	<b>540</b>	<b>565</b>	<b>203</b>	<b>78</b>	<b>15</b>	<b>7 183</b>

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
<b>TOTAL &lt;65</b>	<b>7 194</b>	<b>100.00</b>

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.<sup>8</sup> 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.<sup>9</sup>

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.<sup>10</sup>

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.<sup>11</sup> Cared accommodation is defined as hospitals, nursing homes, hostels and other homes with six or more people.<sup>12</sup> As such,

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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).

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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.<sup>13</sup>

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.<sup>14</sup>

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

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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.<sup>15</sup>

### **Recent initiatives and inquiries for young people with disability in RACF<sup>16</sup>**

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.<sup>17</sup>

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.<sup>18</sup> 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

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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.

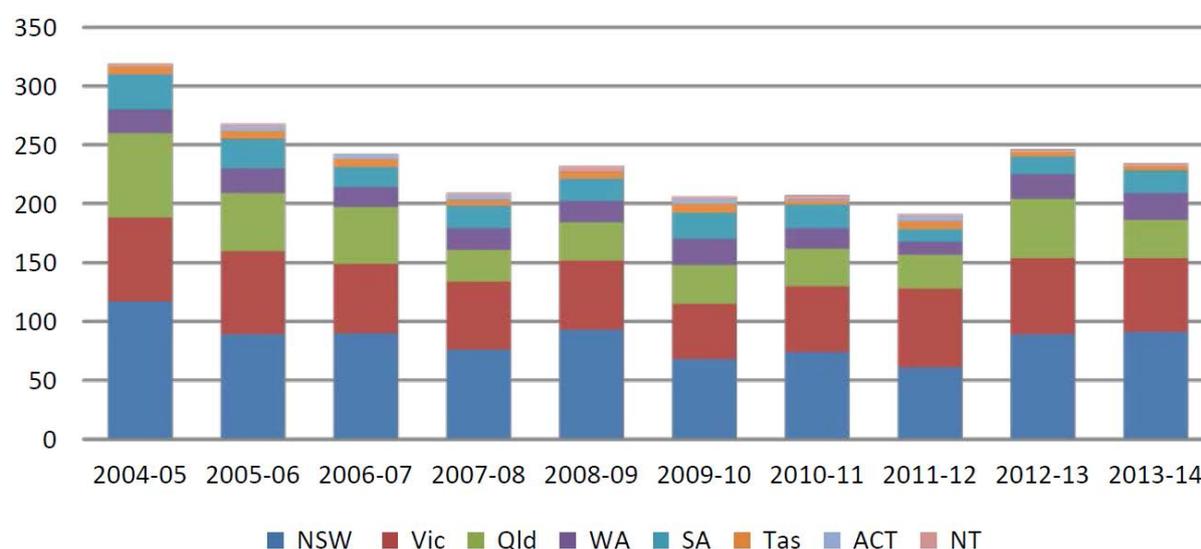
17 Senate Community Affairs References Committee, *Quality and equity in aged care*, June 2005, p. 127, [http://www.aph.gov.au/~media/wopapub/senate/committee/clac\\_ctte/completed\\_inquiries/2004\\_07/aged\\_care04/report/report\\_pdf.ashx](http://www.aph.gov.au/~media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/aged_care04/report/report_pdf.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.<sup>19</sup>

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.<sup>20</sup>

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.<sup>21</sup>

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.<sup>22</sup>

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

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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](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.<sup>23</sup>

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.<sup>24</sup>

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?<sup>25</sup>

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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=6442455539> (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.<sup>26</sup> 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.<sup>27</sup> The importance of carer respite in the context of maintaining family units will be discussed in Chapter 3.

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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](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.

## Chapter 3

### Residential aged care facilities as an accommodation option for severely disabled young people

#### Introduction

3.1 This chapter discusses the following terms of reference:

- (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities; and
- (f) the options, consequences and considerations of the deinstitutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities.

3.2 The committee has received a range of evidence from individuals, families, peak bodies, advocacy and charity groups, and service providers outlining the inappropriateness of aged care accommodation for young people with a disability including but not limited to a lack of:

- independent living options;
- rehabilitation options to facilitate a transition to more independent living;
- lack of age appropriate activities and friends;
- options for supported accommodation;
- advocacy support for young people and their families; and
- a sense of community and economic involvement.

3.3 Most of these issues stem from a young person's lack of choice when deciding the accommodation and support structures that best suit their stage of life and ambitions. Currently, Residential Aged Care Facilities (RACF) are designed for older Australians and are not funded to provide care for young people or people with severe disability. In many cases, young people living in RACF are receiving care more appropriate for elderly people nearing the end of their life. Most of these young people want to participate in education, employment, and social and recreational activities, but are impeded by the RACF environment which does not provide support structures to enable this.

3.4 For those young people and their family who deem RACF the best option for their circumstance, there needs to be a sustained improvement in how aged care providers adapt their facilities and services to meet the requirements of their younger clients.<sup>1</sup>

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1 There are many submissions that outline these issues. See, for example: Mr Peter Szentirmay, *Submission 5*; Ms Kirrily Hayward, *Submission 6*; Ms Joan D'Abreo, *Submission 8*; Mr Chris Le Cerf, *Submission 10*; Mrs Leona Jones, *Submission 13*; Ms Vicky Smith, *Submission 16*.

## International obligations

3.5 Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities. Article 19 of the Convention enshrines the 'right to live independently and [be] included in the community' and asserts:

The equal right of all persons with disabilities to live in the community, with choices equal to others, and [that signatories] will take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.<sup>2</sup>

Further, the International Covenant on Civil and Political Rights states 'that all people with a disability should have the opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements'.<sup>3</sup>

3.6 This chapter will examine how these obligations are not met for young people with a disability in RACF.

## The right to choose a home

3.7 Many submissions to the inquiry raise the concept of social inclusion as being as important as the provision of support services and devices to people with disability. All people regardless of their disability status need to feel connected to the broader community through reciprocal interactions with other human beings. In its submission, JFA Purple Orange eloquently quotes the role of living arrangements—the home—in facilitating that community connection:

Home is more than shelter; it is a place of identity and expression, sanctuary and safety, a place that fosters strength, wellbeing and revival. Home is intimately and inextricably connected to the person. People with disability need to have choice in the place and with whom they live rather than simply accepting an accommodation offer or not. Current accommodation offers rarely relate to social networks, location of family, recognition of culture, personal desires or ambition.<sup>4</sup>

3.8 The catalyst for greater life choices is provided if a person with disability is empowered to choose where they live. This opportunity of choice and control is the natural precursor to an individual 'having valued roles in community life and the economy (often described as inclusion)'.<sup>5</sup> In its submission, Youth Disability

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2 Youth Disability Advocacy Service, *Submission 62*, p. 4.

3 ACT Disability, Aged and Carer Advocacy Service Inc., *Submission 131*, p. [1]. See, for example: Community Safeguards Coalition, *Submission 12*; Australian Human Rights Commission, *Submission 67*; Australian Lawyers for Human Rights, *Submission 133*; Disability Advocacy Network Australia, *Submission 128*.

4 JFA Purple Orange, *Submission 143*, p. 8.

5 JFA Purple Orange, *Submission 143*, p. 8.

Advocacy Services agreed with this proposition citing the results of a research project into disability housing:

[The research project] was clear in identifying that ordinary housing, dispersed within the community, where there is access to individualised supports, consistently outperforms clustered and institutional settings in measures of social inclusion, interpersonal relationships and in material, emotional and physical wellbeing.<sup>6</sup>

3.9 In its submission, Occupational Therapists Australia also discussed the importance of social inclusion and the occupational deprivation that living in RACF can bring. Occupational deprivation occurs when an individual is excluded from the everyday activities of life including social isolation:

76% of our sample of people living in supported accommodation had occasional, or no known contact with friends and outsiders

And a lack of involvement in basic tasks:

Things like ringing the bell for dinner, folding the washing, using a microwave oven to make the hot drinks, watering pot plants—all basic but key occupational tasks offering elements of autonomy and symbolic work-related roles that involve clients, however in many [RACF] such duties are the sole responsibility of nurse or care staff.

And inappropriate activities and poor community engagement:

I often find one of my clients sitting in his bedroom, alone in the dark. Activities of the nursing home are not age appropriate. This was minimal stimulation for a young 22 year old man. I have reviewed the activities available for the nursing home and they are all targeted towards a very elderly age group.<sup>7</sup>

3.10 The concept of social inclusion underpins the next section, the appropriateness of RACF and other types of accommodation.

### **Suitability of Residential Aged Care Facilities and other types of accommodation**

3.11 The committee has received a large number of submissions and evidence from individuals living in RACF, family members, professional bodies, peak organisations and aged care providers. The vast majority of these submissions outlined the inappropriateness of RACF as accommodation for young people under the age of 65.

3.12 The committee received evidence from one family suggesting that some families would struggle on with their children or loved one at home rather than leave them in an RACF:

On her return to the facility, Emily's anger increased to an uncomfortable level. Upon entering and "signing in" we proceeded to her room upstairs,

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6 Youth Disability Advocacy Service, *Submission 62*, p. 2.

7 Occupational Therapists Australia, *Submission 146*, pp 5–7.

which resembled an unused storeroom being the last room at the end of a long corridor with excess equipment and furniture stored outside it. Her bedroom door was locked. We then returned to reception which was unattended to obtain a key. Halfway back up to the room we could not continue the journey. I found myself saying "I cannot put the key in the door, let's go home Ems" and we just left...

I just couldn't bear the thought of leaving my daughter in a place which felt so inappropriate. To me, it felt like I was just deserting her.<sup>8</sup>

Not all families are in a position to take their child or loved one home. These families are left to accept that their loved young person will live in a RACF. This section will discuss the many reasons why an RACF is an inappropriate place for young people to live.

### ***Age appropriate accommodation***

3.13 Many submitters and witnesses agreed that a RACF is not an environment for young people.<sup>9</sup> The committee received evidence that the average age of a resident living in residential aged care is over 85 years old.<sup>10</sup> Many submissions noted the 'cultural distance between the old and the young':

They usually have very different preferences in music, décor, entertainment and generally, just in the ways they fill their day. It is nice to mix together sometimes, but usually young people do not want to live with old people all the time. Why would a young person want to visit their friends in a nursing home?<sup>11</sup>

Further:

A lot of the activities they have there are for elderly people, not for young people. For example they have bingo, where they win chocolates and they play carpet bowls. They do music therapy – people come in to play music and they sing all those old songs, Terry does not participate in any of it.<sup>12</sup>

3.14 Mr Sandra Walker, General Manager at Multiple Sclerosis Ltd spoke about the difficulty young people have when forming friendships in a RACF:

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8 Name withheld, *Submission 41*, p. [1].

9 See, for example: Ms Katy Skene, *Submission 19*, p. 1; Ms Karen Higgins, *Submission 25*; Ms Bev Shalders, *Submission 32*.

10 Ms Susan Shapland, General Manager—Client Services, Multiple Sclerosis Society SA & NT, *Committee Hansard*, Darwin, 1 April 2015, p. 12. See, for example: Dr Ken Baker, Chief Executive, National Disability Services, *Committee Hansard*, Sydney, 19 February 2015, p. 6. Royal Australian and New Zealand College of Psychologists, *Submission 50*, p. 2.

11 Ms Jennifer Nolan, *Submission 66*, p. [2].

12 Mr Terry and Mr Darrell Bainbridge, *Submission 71*, p. [2].

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Living in a nursing home has meant I have lost all my friends. Even though I make friends with other elderly residents, they die. Being surrounded by death is upsetting and depressing.<sup>13</sup>

### *Access to services*

3.15 The committee received evidence highlighting many of the inherent shortcomings that exist for young people living within a sector designed to care for people in the final years of their lives. These include inadequate access to rehabilitation, non-availability of certain supports due to funding restrictions within the aged care sector, and the loss of personal effects and pets.

3.16 There is a very strong link between access to adequate rehabilitation and independent living for people with severe disabilities. Many young people have been able to live relatively independently due to regular rehabilitation and occupational therapy only to regress upon entering a RACF when those services are not provided.

3.17 Where services are provided they are often inadequate. Mr Darrell Bainbridge relayed the current situation in his brother's RACF where 'they have a physiotherapist at the nursing home that has 60 residents to consult in only two days a week'.<sup>14</sup> Mrs Ann Newland, mother of Michelle, noted the lack of progress made during her daughter's stay in a nursing home:

During this time Michelle spent 23 hours in bed with very few visitors, apart from my husband and me. We visited her every day and brought her home on weekends. Michelle made no gains in the nursing home, and in fact the gains made in rehab were compromised. It was a very hard time for all of us, filled with great sadness, immense stress, fear and loneliness. Every goodbye whilst Michelle was in the nursing home was heartbreaking. I would cry all the way home.

Michelle was described during her stay in the nursing home as:

[O]nly saying a few words and... walking, but not very well, still requiring a wheelchair. She was incontinent. She was fed through a PEG tube and could not even swallow her own saliva. She required 24-hour care.

3.18 This description contrasts with the 'vibrant, beautiful person' attending the committee's Melbourne public hearing who stood and was acknowledged with applause by the committee.<sup>15</sup> Nominally RACFs offer rehabilitation services but the actual availability of the service and its provision are patently inadequate, and do not facilitate people to regain some or all of their independence. The importance of rehabilitation for this cohort will be expanded on in Chapter 4.

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13 Ms Sandra Walker, General Manager—Service Innovation, Multiple Sclerosis Ltd, *Committee Hansard*, Melbourne, 11 March 2015, p. 31. See also, Mr Terry and Mr Darrell Bainbridge, *Submission 71*, p. [3].

14 Mr Terry and Mr Darrell Bainbridge, *Submission 71*, p. [3].

15 Mrs Ann Newland, *Committee Hansard*, Melbourne, 11 March 2015, p. 46.

3.19 Inadequate provision of services leads to some families feeling that they have to fill these gaps. Ms Nicole Everingham still 'provides daily support for her son, despite the involvement of 2 funded service systems' showing that the 'overall system is utterly and completely deficient in its capacity to deliver the care my son so obviously needs'.<sup>16</sup>

3.20 Often different government departments cannot agree on who is responsible for the provision of a particular service. These disagreements exist between mainstream services (for example, health, housing, aged care) and the disability sector about where responsibility lies for funding particular services or supports. The committee received evidence from a number of witnesses about people requiring wheelchairs who were not being given access to them.

The only reason Daniel has a wheelchair is that the specialist who was looking after him was kind enough to pay for it, because I did not have the money after him being in hospital for a year...<sup>17</sup>

Our daughter has been given, by somebody who is very kind, a second-hand wheelchair. I was promised by the NDIS 12 months ago that she would have a purpose-built wheelchair. She is not going to live that long and I want that wheelchair really badly.<sup>18</sup>

3.21 This siloed approach to service provision seems to focus more on a department minimising its costs and, where possible, transferring those costs to other state or commonwealth departments and agencies rather than achieving outcomes for individuals. The committee notes that decisions made at a macro-economic level have significant tangible impacts on individuals and the basic provision of supports and services such as wheelchairs. The committee also recognises that this siloed approach manifests as an inability to work across agencies. This will be explored further in Chapter 4.

### ***Social inclusion and individualism***

3.22 Occupational health and safety requirements in many residential care settings have created homogenised environments in which many young people do not feel at home or do not feel that they can express their own personality. In her submission, Marina Nikolova, currently residing in hospital and who will shortly move into a RACF, noted that:

Prior to admission [to hospital], I was able to invite friends to my flat, care for my cat named "Kitty" and look after my pot plants. Kitty is all I have in life and I cannot have a cat in any of the aged care facilities. It is very distressing to know that I need to relinquish Kitty to Pet Rescue or to a

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16 Ms Nicole Everingham, *Submission 111*, p. [4].

17 Ms Nicole Everingham, *Committee Hansard*, Sydney, 19 February 2015, p. 33.

18 Mrs Leona Jones, *Committee Hansard*, Melbourne, 11 March 2015, p. 44. See also: Name withheld, *Submission 22*, p. [2]; Ms Kirrily Hayward, *Submission 6*. Ms Hayward lives in a nursing home as a result of pressure sores that require on-going treatment—this is a health issue rather than one of disability.

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person or family who will love her as I do. I already really miss my "old life" and knowing that I will have to sell my furniture and effects is also very upsetting and depressing.<sup>19</sup>

3.23 Ms Deborah Farrell of Multiple Sclerosis Limited discussed staff patient relations relating a young man's feedback on living in an RACF:

You don't live in residential aged care, you just exist...

It was the loss of freedom, loss of respect, loss of intelligence. Pretty much you were treated like a person needing aged care, that you haven't got a brain.

Another young woman described her interactions with staff at the RACF:

The staff—they were almost robotic. They did their work but not with any feeling. Like they were milking cows.<sup>20</sup>

3.24 Many submissions focused on the social isolation experienced by young people living in RACF. In addition to inappropriate age-related activities and a lack of opportunities to remain independent, the resources to allow people to encourage social and community engagement are simply not available in the aged care sector. For example, the committee received evidence about the lack of flexibility around bedtimes and meals:

The times that the meals are structured do not suit them, nor does bedtime. In aged care your staffing numbers get lower at the end of the day. That is when those younger people say, 'Excuse me, I want to go to bed at 11.' Our staff finish at 11 and we bring in night staff. We do not have three people to put someone with severe disabilities to bed at 11 o'clock. Those things really do affect people. They have to make a lot of sacrifices, those younger people, because they are compromising.<sup>21</sup>

3.25 Mrs Gail Palmer of the MS Society of WA spoke about the problems of imposing a strict regime on people who must make difficult decisions about their daily activities due to their illness:

You are told what time to shower. One of the chronic problems with MS is that people get fatigue. Almost 100 per cent of people get fatigue. For a person with MS, they might decide in the morning: 'Will I shower, or will I have coffee with my friend? I have to do one or the other; I cannot do both.' When you are living in an aged-care facility, there are rules and regulations that everyone will be showered every day, and it will be done in the morning at that time—I know that some are better, but it is still very often

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19 Ms Marina Nikolova, *Submission 152*, p. [3].

20 Ms Deborah Farrell, Senior Manager, NDIS Futures, Multiple Sclerosis Limited, *Committee Hansard*, Melbourne, 11 March 2015, p. 31.

21 Mrs Yvonne Kromkamp, Chief Executive Officer, Mt St Vincent Nursing Home and Therapy Centre Inc., *Committee Hansard*, Hobart, 12 March 2015, p. 12.

like that. It is for staffing: you have x number of staff on because that is when the personal care is done. And your choices are taken away.<sup>22</sup>

3.26 The ACT Disability Aged and Carer Advocacy Service Inc (ADACAS) submitted that '44% of younger people in aged care will receive a visit from friends less than once a year; 34% will never participate in community based activities such as shopping; and 21% will go outside the home less than once a month'.<sup>23</sup> These statistics are symptomatic of the social dislocation that many of these young people experience. Lack of opportunity to engage in suitable community and other physical activities can result in entrenching unhealthy and introverted behaviour, further alienating these young people from society:

One of our younger clients who lives in a nursing home, for example, spends his days outside smoking, watching television or playing video games as his sole forms of entertainment. He has very few other options available to him.<sup>24</sup>

3.27 The committee also heard that residents of RACF are 'only allowed 52 overnight days of social leave per financial year where they are absent from the facility':

This does not provide for residents' who may have family and friends and want to stay with them overnight on the weekends as well as for holiday periods. This restriction limits residents' social interaction and increases their social isolation.<sup>25</sup>

3.28 Bullying of residents in aged care, their families and staff was raised as an issue including 'verbal aggression, demeaning behaviour, the failure to respect people's privacy, [in particular] the privacy of women using the assisted toilet'. Mr Daniel Black, an RACF resident recounted a bullying incident:

The staff member who does most of the bullying in this facility bullied me. I had a fall in the assisted toilet, the [registered nurse (RN)] at the time saw me fall and asked the worker to assist me. I told her that I need her to lift the chair out of the way. She said it was 'too heavy' (it weighs 16.5 kgs) and ran it over my legs. The RN and I both made a formal complaint to the

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22 Mrs Gail Palmer, Manager—Community Programs, Multiple Sclerosis Society WA, *Committee Hansard*, Perth, 16 February 2015, p. 16.

23 ADACAS, *Submission 131*, p. 2.

24 ADACAS, *Submission 131*, p. 2. See, for example: Ms Nicole Everingham, *Submission 111*, p. [2]. Ms Everingham's son, Daniel, shares a room with a man 'in his 80's...who recently stopped wearing underwear and pants which has put an end to my younger son wanting to visit [Daniel]'.<sup>25</sup>

25 Queensland Aged and Disability Advocate, *Submission 92*, p. 4.

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Manager but nothing was done. It was swept under the carpet like it normally is.<sup>26</sup>

3.29 The issue of food quality and even the dignity of eating were raised. Mrs Palmer explained that young people are fed 'a brown splodge, a green splodge and some other splodge on a plate' and sometimes fed as part of group of four. Meals are strictly timed with food removed at the end of an allocated time. These young people lose the 'dignity' of choosing when to start and finish a meal, and whether to enjoy it alone or with company.<sup>27</sup> Dr Adrienne Withall of the University of New South Wales (UNSW) related the experience of a young woman who would spend brief periods in an RACF as a form of respite:

They keep mashing up my food. I don't need my food mashed up. I come to respite because I know my husband needs a break...but I do not need my food mashed up, and I cannot get an internet connection. At least if I had the internet I could sit in my room and I would still have access to the outside world, but I cannot do that, and so I feel very alone.<sup>28</sup>

### ***Mental health***

3.30 A common thread throughout the evidence received by the committee is in relation to the poor mental health of young people caused by the factors previously discussed. In its submission, Catholic Social Services Victoria noted 'the difficulty for young people in nursing homes to create age appropriate friendships within their 'home': this can impact on their quality of life and exacerbate pre-existing mental health issues'.<sup>29</sup> There is a heavy emotional impact on individuals with one submitter 'describing himself as the "living dead" and "If I was a dog, you would put me down"'.<sup>30</sup> Occupational Therapists Australia identified a number of key mental health issues that will affect young people living in RACF including grief, loss and depression; temporal concerns—lack of autonomy and meaning in daily tasks; and loneliness.<sup>31</sup>

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26 Mr Daniel Black, *Submission 21*, pp 4–5. See also: Mrs Leona Jones and Mr Daniel Black, *Committee Hansard*, Melbourne, 11 March 2015, pp 42–44; Ms Nicole Everingham, *Submission 111*, p. [2]. Ms Everingham's son, Daniel, 'displays signs of being abused and neglected.' Children with Disability Australia, *Submission 102*, pp 12–13. 'CDA is concerned that children and young people who are living in residential aged care facilities are extremely vulnerable to abuse.'

27 Mrs Gail Palmer, Manager—Community Programs, Multiple Sclerosis Society WA, *Committee Hansard*, Perth, 17 February 2015, p. 16.

28 Dr Adrienne Withall, Senior Lecturer, UNSW, *Committee Hansard*, Sydney, 19 February 2015, p. 45. See also: ADACAS, *Submission 131*, p. 2.

29 Catholic Social Services Victoria, *Submission 132*, p. 10.

30 Mrs Keryn Hickey, *Submission 106*, p. [1].

31 Occupational Therapists Australia, *Submission 146*, p. 8.

### ***Aged care not young care***

3.31 The committee received a number of submissions from organisations that currently operate aged care facilities indicating that accommodating young people in their facilities is not a suitable long term option. Anglicare Australia submitted that one of its member organisations, Benatas:

[R]ecognises [that] aged care services are not designed for this cohort. The issues relate primarily to the lifestyle needs of younger people in relation to service choice, and here are many cultural, lifestyle and sexuality considerations around providing care for people in these circumstances, which Benatas is not well placed to provide.

For self-evident reasons, many of the services Benatas provides are age specific, and whilst adequate physical care may be able to be provided, lifestyle options and personal support suitable for younger people are not.<sup>32</sup>

3.32 Further, Aged and Community Services Australia's submission noted:

Aged care services are designed to address the natural processes of ageing, not disability; the term 'disability' does not appear anywhere in the *Aged Care Act*. While there are provisions for supporting younger people in residential aged care when there are no other options available, this is clearly not the intention of aged care services.<sup>33</sup>

### ***The financial impost of living in aged care***

3.33 The committee received evidence about the debilitating fees paid by young people living in aged care and the financial destitution this places them in. Mr Daniel Black, an RACF resident submitted:

I pay 85% of my pension to the aged care facility. I'm not eligible for rent assistance because I live in a nursing home. I'm left with \$50 per week for chemist bills including putting my medications in Webster packs, which is required by the facility. I have three Webster Packs made up each week and at a cost of \$17 dollars just for the pack, the medication is an additional cost, so that's \$51.00 per week gone already. I'm living in the red, I pay \$45.00 per week on cigarettes, about \$20.00 per week for my phone. I owe the chemist money, I owe the facility money and I owe Telstra money, it's really stressful. Occasionally I buy a Tatts ticket on the off chance that I'll win and get a little bit ahead...

Since my admission to [RACF], my ISP [Individualised Support Package] has been cut to \$25,000 and they want to cut it to \$6,000. I spend my

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32 Anglicare Australia, *Submission 164*, p. 3. See also: Salvation Army National Secretariat, *Submission 33*, pp 3–4; Catholic Health Australia, *Submission 58*, p. 2; Northcott, *Submission 70*, pp 4–5; HammondCare, *Submission 87*, p. 1.

33 Aged and Community Services Australia, *Submission 73*, p. 5.

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\$25,000 on music therapy, massage therapy and for [carers to] come in to put my clothes away when my budget allows.<sup>34</sup>

This is in stark contrast to the 'happy years' when Mr Black lived as a person with disability in his family home with his wife and pets adequately funded through a Disability Support Pension and an Individualised Support Package (ISP).<sup>35</sup> The committee notes that those living in aged care are deemed to have access to a number of supports—that are not adequately provided—and, as such, have their ISP reduced based on this false assumption.

3.34 There are other financial imposts placed on young people who live in aged care facilities. Ms Lorraine Gibbs of the Darwin Community Legal Service told the committee that an 'income and assets test applies to anybody moving into an aged care facility' and that they may have to pay a bond in order to secure an aged care placement. This has profound consequences on that person's financial capacity to move out from an RACF particularly if they had to sell a house or flat to enter the facility:

My concern is that if it is a younger person, and we are particularly wanting to get younger people out of a facility, and somebody moves in today, that is what would be the arrangement, as far as I am aware. If they were to stay there for, say, 10 years but they needed to sell their unit to pay the bond, then in 10 years time they will get some of that bond back, but meanwhile property prices or whatever may have escalated—and establishing themselves back out in the community may be a lot more difficult than it would be if that did not apply.<sup>36</sup>

3.35 The committee notes the financial disadvantage that some young people are placed in whilst living in RACF and the impact that this has on those seeking to transition into other accommodation.

### ***When is aged care suitable?***

3.36 For the vast majority of young people, aged care is a completely inappropriate place to be accommodated. However, in some circumstances aged care facilities can be an appropriate option for young people, but only if the aged care sector seeks innovative ways to deliver this care. Ms Maddy Archer noted in her submission that she has lived in a nursing home for eight years and is 'quite comfortable', as she lives

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34 Mr Daniel Black, *Submission 21*, p. 6. See also: Mr Russell de Burgh, Branch Manager, Policy and Evaluation Branch, *Committee Hansard*, Canberra, 15 May 2015, p. 41. Mr de Burgh told the committee that a facility can charge a basic daily fee of 85 per cent of the single rate of the aged pension or \$47.49 per day. This contribution is on top of the Commonwealth funded contribution of \$56 000 per person living in residential care.

35 Mr Daniel Black, *Submission 21*, p. 3. See also: Mr Daniel Black, *Committee Hansard*, Melbourne, 11 March 2015, p. 42; Additional Information, Ms Yvonne Kromkamp, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents) (accessed 15 April 2015).

36 Ms Lorraine Gibbs, Team Leader and Senior Advocate, Aged and Disability Advocacy Service, Darwin Community Legal Service, *Committee Hansard*, Darwin, 1 April 2015, p. 3

in a two bedroom apartment, not in the main facility, allowing her to retain a sense of independence.<sup>37</sup> Mt St Vincent Aged Care Home in northwest Tasmania has built a separate wing to accommodate younger residents. This wing is separate from the main facility and allows the residents more age appropriate living arrangements. It even allows the residents to come and go with their own electronic key.<sup>38</sup> Some submitters acknowledge that with an ISP to fund appropriate supports, a young person can 'continue to live life fully in an aged care facility which is open to partnership and person centred support'.<sup>39</sup>

***Appropriateness of people with Younger Onset Dementia, intellectual disabilities and degenerative disease being housed in aged care dementia wards***

3.37 The committee received evidence about groups of young people with specific needs and/or challenging behaviours that are difficult to manage in the aged care environment.<sup>40</sup> Professor Brian Draper and Dr Withall of UNSW explained the behavioural issues associated with a growing number of younger onset dementia patients being accommodated in RACF:

There is this group, particularly younger males, often with alcohol related problems or other brain damage to the front part of the brain, where behaviours can get extremely challenging, and there are very few facilities across the country that can adequately provide quality care for these people...

[I]f you put people who are prone to behavioural disturbance in a unit where they are sitting...with no stimulation, no meaningful engagement, then yes, that will bring it on.<sup>41</sup>

3.38 Often, aged care workers have no or little training or experience working with disabilities. Challenging behaviour can manifest when young people with disability 'have significant impairments in their communication and behaviour becomes a mechanism for communicating things like discomfort in an environment, pain or other physical distress, or sensory or emotional distress'.<sup>42</sup>

3.39 In its submission, Down Syndrome Victoria noted that people who have Down syndrome have a 'high chance of acquiring age related health conditions,

37 Ms Maddy Archer, *Submission 4*, p. [1]. She would like to transition to a 2 bedroom unit independent unit in order to live more independently when housing is available. See also, Mr James Bailey, *Submission 30*, p. [2].

38 Ms Yvonne Kromkamp, *Submission 84*, p. 1.

39 Inability Possibility, *Submission 82*, p. 4.

40 People with Disabilities WA, *Submission 158*, p. 10. Challenging behaviour is defined as behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.

41 Professor Brian Draper and Dr Adrienne Withall, *Committee Hansard*, Sydney, 19 February 2015, p. 46. See also: Professor Brian Draper, *Submission 3*, pp 1–2.

42 People with Disabilities WA, *Submission 158*, p. 10.

including dementia, in midlife—around 35 to 50 years—often with a more rapid onset and deterioration in cognition, than the general population'. However, those with Down syndrome already have a range of cognitive and language deficits which may be exacerbated by other health conditions and present as challenging behaviour. Diagnosis and treatment of dementia—in its development and consolidation phases—for those with Down syndrome needs to be managed by suitably qualified professionals. Traditional dementia wards in aged care facilities often do not have the experience required to treat those with intellectual disabilities.<sup>43</sup>

3.40 A range of other groups including those diagnosed with Multiple Sclerosis, Alzheimer's, Huntington's disease and motor neurone disease require specialised knowledge to support and assist with living arrangements. This specialist support often cannot be provided by aged care workers.<sup>44</sup> Training of aged care workers to work with people with disability will be discussed further in Chapter 4.

### *Institutions and congregate care*

3.41 Many submitters to this inquiry view this issue as broader than simply young people living in aged care and instead describe it as an institutional issue. Melba Support Services related the story of Mr Colin Rose who described the:

[L]ows of being accommodated in aged care and other congregate care services with people I had little in common with and with whom I would not, had other options been available, have chosen to live with.<sup>45</sup>

3.42 Ms Kathryn Bruce outlined some of her concerns about the group home where her daughter lives:

Funding appears to be on a shoe string, and always done [at the] cheapest possible. Staff are barely qualified, and although they mean well, and try really hard, they are often not highly experienced or skilled in working with those with disabilities. Their pay is low, meaning they often leave to get a better job maybe with more regular hours.

Further, Ms Bruce noted:

We do appreciate how difficult it must be to run houses, however we as parents would like more say in who our daughter lives with and who works with her.<sup>46</sup>

3.43 The Office of the Public Advocate Queensland (OPAQ) stated that there were 131 people with severe intellectual or cognitive impairment living as long-stay

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43 Down Syndrome Victoria, *Submission 48*, p. 1. See also: NSW Council for Intellectual Disabilities, *Submission 75*, p. 1; UNSW Department of Developmental Disability Neuropsychiatry, *Submission 153*, pp 1–3.

44 For example, see Multiple Sclerosis, *Submission 46*; Alzheimer's Australia NSW, *Submission 60*; Australian Huntington's Disease Association, *Submission 79*; Motor Neurone Disease Australia, *Submission 123*.

45 Melba Support Services, *Submission 78*, p. 3.

46 Ms Kathryn Bruce, *Submission 145*, pp [1–2].

residents in Queensland public health facilities or institutions. These facilities include public residential health facilities, public aged care facilities, hospitals and other health services, and mental health facilities. OPAQ noted that 'it is neither acceptable or appropriate for people with disabilities to continue living in hospitals or other institutions' citing poor access to the community, educational and vocational opportunities. OPAQ noted that many of these institutional facilities 'are not home-like':

[D]espite the fact that many people with disabilities live there, some for most of their lives. Many people with disability in health facilities sleep in hospital beds in ward-type environments with other people. This is despite the fact that hospital beds are often not required for their disability (for example if they have an intellectual disability). It was submitted to the Public Advocate that the living conditions in one particular health facility:

"directly contrasts how an ordinary home would look; dividing a multi-story building into living areas and providing sleeping arrangements where up to four people share a room is far from the ordinary home. Indeed, the centre is reminiscent of a nursing home which perpetuates the stereotype that people with a disability are sick and/or close to death."<sup>47</sup>

3.44 The committee received evidence about the symbolic importance of removing young people from RACF as a first step in recognising that institutions are not appropriate places for young people to live:

The more we condone young people in Residential Aged Care Services, the more we reinforce the message that people with disabilities belong in institutions [and not in the community].

Further:

Young people, regardless of whether they have a disability must have the right to experience a full life of adventure and exploration. They are not dying nor are they frail. They are vital to the future of our society and as such must be seen, heard, engaged with and learnt from.

Living in an institution rather than in the community means that these young people cannot be 'seen, heard, engaged with and learnt from'.<sup>48</sup> The Office of the Public Advocate Victoria recommends that all Australian Governments 'commit to a timeframe in which all remaining congregate care (institutions) for people with disability will be closed'.<sup>49</sup>

3.45 This section has established that RACF is inappropriate for a number of reasons as they are not designed or funded to provide care for young people. The committee notes that there needs to be a paradigm shift in how society views young people with disabilities and how services are provided to them, not only in aged care facilities, but in all institutional settings. BaptistCare says:

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47 Office of the Public Advocate Queensland, *Submission 134*, p. 2.

48 BaptistCare, *Submission 130*, p. 2.

49 Office of the Public Advocate Victoria, *Submission 110*, p. 3.

As a nation, we need to be better at designing services for individuals so meeting resource constraints are not the priority. We also need to be mindful of how such services restore balance in terms of the things that are free—the natural networks of individuals. Children with profound disabilities access supports and services through the early years, these services often change when they reach high school age, and they change again post school. Their visibility and engagement through such early to teenage years are not in a bubble, they involve having others around them. Yet a time comes when our systems bring all of that to an end.<sup>50</sup>

3.46 In the next chapter, a range of different housing and support models will be examined.

### **Supporting families and individuals to stay at home or in the community**

3.47 The previous section noted many of the reasons why it is inappropriate for young people to live in RACF and institutions. This section will explore the options for enabling young people to continue living with their families or independently in the community.

3.48 Families Australia's submission recognises that young people with severe disabilities are members of families and communities, that 'young people may have children and a partner as well as parents, siblings and broader family members' and the centrality of these familial relationships in their lives.<sup>51</sup>

3.49 The committee heard that many young people living in aged care yearned to participate in normal relationships with friends and family like others their own age would expect. Mr James Bailey explained that his 'needs and interests are exactly what you'd expect of a twenty-eight year old man' and that like most twenty-eight year olds, every Wednesday night he and a friend:

Go to the dockyards (pub) and have a meal and then some drinks then on to cold rock for an ice cream or a milk shake...

I am out most days, and often on Saturdays at mum and dad's place.<sup>52</sup>

3.50 In its submission, JFA Purple Orange contained an excerpt of an interview with a young person explaining why it is important to live at home:

[You have an] independent back yard, having your own things, family visiting. The family can sit in a casual setting, and you don't get that in a nursing home—you have to go to a day area. There's more time to sit—no time limits or restrictions. You can go to bed anytime you like. A better environment.

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50 BaptistCare, *Submission 130*, p. 2.

51 Families Australia, *Submission 42*, p. 2.

52 Mr James Bailey, *Submission 30*, p. [3]. Although Mr Bailey currently lives in an aged care facility, he has his own room and bathroom. He also lives with considerably more freedom than other young people living in aged care.

The committee notes the importance of living in an environment—whether independently, with friends or family—that fosters these relationships and the support structures they create.

3.51 Australian Home Care Services (AHCS) currently supports over 30 people to live in supported accommodation.<sup>53</sup> AHCS found that young people in this environment:

[E]ngage with and access their communities more frequently, at times developing friendships outside of the service delivery models; develop skills to use services and facilities within their communities, including undertaking personal shopping, banking and recreational and leisure interests and re-establish family connections and their roles as parent, partner, sibling and friend...

Importantly there are options, designed to help them live the life they have chosen and the support to participate in the things that give them purpose.<sup>54</sup>

3.52 The committee also received evidence suggesting it would be more cost effective to support young people in their own homes than in RACF. As Mr Chris Anastasiou notes:

The government currently pays significant amounts of money to nursing homes. We could have gone home with 50% of that money, i.e. the \$150 000 for one person to live in a nursing home could have kept both [Lisa and Chris have MS] at home. We should have had choices rather than others deciding where we should live. We should have had access to more care at home and a case manager assigned to us to explain our funding options and to make plans for our future. We could have stayed at home longer and we could have avoided a crisis.<sup>55</sup>

3.53 Mr Anastasiou concluded his submission by sharing why it was important for him and his wife to be living at home again:

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53 Supported accommodation services can include group homes, community residential units, and support to live individually or in a family home. Support may range from several hours per week up to full-time care. Support is 'based on individual needs and promotes community participation, relationship building, skill development and maintenance. Accommodation is usually offered in shared housing with the residents supported by a team of staff who usually work according to a roster'. See Victorian Department of Health and Human Services, *Disability Supported Accommodation*, <http://www.dhs.vic.gov.au/for-service-providers/disability/accommodation/supported-accommodation> (accessed 5 June 2015).

54 Australian Home Care Services, *Submission 94*, p. 1. See, for example: Melba Support Services, *Submission 78*.

55 Mr Chris Anastasiou, *Submission 72*, pp 1–2. See also: Office of the Public Advocate Queensland, *Submission 134*, p. [3]. 'In many cases it does not make good economic sense to care for people in acute hospital beds, for example, when that same person could be receiving more appropriate support in a community-based setting at a significantly reduced cost'.

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Now I'm home, I can go out the back and take in the view of the mountains and draw a deep breath without hearing the screams from the room next door.<sup>56</sup>

3.54 The committee also notes the importance of young people being able to live independently in their own home or their own room in supported accommodation. Ms Anita Geach-Bennell and her husband currently support their two daughters to live independently in their own home. Ms Geach-Bennell outlined the importance of this independent living arrangement to her daughters as a means of participating in society and everyday activities:

While I am alive, my girls will not enter a nursing home. They will continue to access their community, they will ride their bikes, and they will go to shows.<sup>57</sup>

When Nicole and Craig Jones moved to Karroong:

Nicole was ecstatic, she wanted everyone to know about where she was living and how it was going for her. She was proud of her room and loved decorating it.

For Craig, it was important that:

He could bring his beloved dog Dusty with him...<sup>58</sup>

### ***Respite—adequacy and access***

3.55 Respite can be the most effective mechanism to support a young person's primary carer—especially if that carer is a family member—and allow a young person to remain in their family home. Respite care allows the primary carer to take a break from caring duties. Respite may be in the form of partial care—where another carer may undertake specific tasks such as cleaning, shopping or taking a young person on an outing—or full care, where another carer undertakes all caring duties for a short defined period lasting days or weeks. This fulltime care can take place in the family home or in another supported accommodation facility. Respite allows the primary carer to have a mental and physical break from the demands of caring. It can also allow them to focus on other caring duties or responsibilities they might have such as raising other children, working or studying. Respite can be the difference between a young person being relinquished to an institution or remaining in their own home with their family.

3.56 Mr Gregory McMahon of Carpentaria Disability Services emphasised the importance of respite for maintaining the family unit:

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56 Mr Chris Anastasiou, *Submission 72*, p. 2. See also: Mr Darryl Bainbridge, *Submission 71*, p. [5]. Mr Bainbridge stated that: 'Terry is so much happier at home, his brother gets him up in the morning and makes him a cup of coffee and he yells out "What's going on?"—and he is just so much happier.'

57 Ms Anita Geach-Bennell, *Submission 61*, p. 3.

58 Ms Leona Jones, *Submission 13*, p. [5]. Karroong is a supported accommodation facility. 'Karroong' is the Aboriginal word for 'Home'.

[F]amilies could certainly benefit from more respite. You cannot give too much. You can term that as 'early intervention' if you want...

Coming back to the question of how you would do it better, for me it is: keep families together. If you build those resources and you give them those regular breaks—that is not me trying to get my service bigger—that respite can go right across. Everyone can be in that game, because it can be done in the community. I would much rather see it happen in the community than in a centre based facility.<sup>59</sup>

3.57 Evidence to the committee suggested that there is an inadequate supply of respite leading to people moving into aged care by 'default'.<sup>60</sup> The Australian Bureau of Statistics states that over 81 per cent of resident parent primary carers have 'never used respite care'.<sup>61</sup> A common story was relayed by Dr Withall: 'We can't manage any more. There's no respite. We can't get a break.'<sup>62</sup> Others, like Ms Robyn Keyte, feel prevented from leaving the hospital or an RACF as:

[W]hen we go out, if we leave, we have not got respite anymore. We are not allowed to come back. So that is another issue. Our carers need rest but also we need somewhere to go that knows how to turn us—and not to nursing homes.<sup>63</sup>

3.58 Ms Natalie Ryan of the service provider Royal Rehab highlighted a key constraint hindering the availability of respite—funding:

We have supportive accommodation vacancies. In some instances we could accommodate them, but we understand there is a process involved. So we cannot even offer respite. We cannot even offer in-home behaviour support. We cannot offer anything, because there is no funding, and they have to go through this process that often takes many years.<sup>64</sup>

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59 Mr Gregory McMahon, Chief Executive Officer, Carpentaria Disability Services Incorporated, *Committee Hansard*, Darwin, 1 April 2015, p. 15

60 Mr Scott Avery, Policy and Research Director, First Peoples Disability Network, *Committee Hansard*, Sydney, 19 February 2015, p. 2. See, for example: Mr Graeme Samuel AC, President, Alzheimer's Australia, *Committee Hansard*, Sydney, 19 February 2015, p. 13.

61 Answer to Questions on Notice, Australian Bureau of Statistics, June 2015, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents), (accessed 4 June 2015). This equates to over 143 000 parent carers who have not accessed respite care.

62 Dr Withall, Senior Lecturer, UNSW, *Committee Hansard*, Sydney, 19 February 2015, p. 48. See, for example: Mrs Anita Geach-Bennell, *Submission 61*; Children with Disability Australia, *Submission 102*, p. 13. Young children are being relinquished 'as an absolute last resort by families who are at breaking point due to the lack of support they receive to care for children.'

63 Ms Robyn Joy Keyte, *Committee Hansard*, Perth, 17 February 2015, pp 25–26.

64 Ms Natalie Ryan, Independent Living Coordinator, Royal Rehab, *Committee Hansard*, Sydney, 19 February 2015, p. 36.

3.59 Dr Withall noted that 'not only is there a lack of [respite] services that can accept [young people], but they also find it very difficult to handle people who are quite young and fit and agile'.<sup>65</sup> Dr Withall continued:

[P]eople do want to live in the community for as long as possible and families want to stay together for as long as possible. It is much more important for young onset dementia. That would be easier if there was more respite. That is a major unmet need in young onset dementia because there are quite a number of units that just say, 'The person is younger; we're going to have difficulty finding a place for them,' or, 'They have a lot of behavioural symptoms,' so it comes around again—'We're going to have difficulties finding a respite place for them.' So families tend to get into crisis with young onset dementia.<sup>66</sup>

3.60 Some carers have been able to access respite, only to find the care provided to be inadequate. Mrs Vicki Brous found that when she carefully chose a 10 day respite for her husband, many fundamental items relating to his care were overlooked. This resulted in the respite stay being more stressful than if he had simply stayed at home. Mrs Brous noted that 'after this experience, we will never trust an aged care facility to provide [respite] again'.<sup>67</sup>

3.61 The committee recognises the importance of adequate and accessible respite as a means to support young people and their family carers.

#### ***Transition—crisis driven or planned***

3.62 Many young people will need to transition from one form of accommodation to another at various points in their lives. There are many iterations of the transition journey but fundamentally it will involve movement to or from the following—hospital (acute care), supported accommodation, RACF, family home, shared or independent living. Transition, when coupled with planning and choice, can result in outcomes that suit the young person and their family. However, if transition is crisis-driven—for example, a parent carer dying suddenly or the young person's condition rapidly deteriorating—then often decisions relating to the new accommodation are not considered or informed, and ultimately not best suited to the young person. Many submitters have noted the lack of advocacy and support to assist young people and their families to make decisions:

There is a long-standing fundamental problem in the provision of support needed by young people with severe disabilities. The result has been families under enormous pressure as they seek to meet the needs of their children and many young people with severe disabilities being institutionalised, including in aged care facilities, for want of appropriate support in the community. Also, health services have been inadequate to

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65 Dr Adrienne Withall, Senior Lecturer, UNSW, *Committee Hansard*, Sydney, 19 February 2015, p. 42.

66 Dr Adrienne Withall, Senior Lecturer, UNSW, *Committee Hansard*, Sydney, 19 February 2015, p. 47.

67 Mrs Vicki Brous, *Submission 37*, pp 3–4.

meet the often complex health needs of young people with severe disabilities.<sup>68</sup>

3.63 The importance of providing support to families of young people, particularly in times of crisis was highlighted by Mr Gordon Trewern, CEO of Nulsen Disability Services:

Often the focus is on the person with a disability. There also needs to be a focus on the family supporting the person with a disability. The crisis is certainly central to the person who has suffered the acquired brain injury, but the family itself is going through a huge trauma. Often that impedes them from making the right decisions or asking the right questions. 'Is this the right direction we should be going in?' 'Does this service provider have the skill and expertise to provide support to my child or partner?'<sup>69</sup>

3.64 The committee received evidence from Ms Stephanie Gotlib outlining the principles behind successful transition from hospital to home:

The other model—and I can only speak of how it was when I was there, and I know it has changed since then—is the Family Choice Program, which was for children with complex medical care needs. But they had a home care nurse who trained family and a range of attendant carers to provide the complex care. It was so kids did not have to live in hospital. Then they had ongoing case management and looked at what the family's needs were, what the children's needs were, or vice versa, and looked at how they could wrap the services around the child, their developing needs and their life. It was an expensive, Rolls Royce kind of program at the time when I was there, but it worked and worked well.<sup>70</sup>

These principles—early intervention, support pre- and post-transition, recognition of the role of the carer, and a discussion with the family that leads to choices—when adopted together result in quality and sustainable outcomes for young people and their families. The issue of transition, advocacy and support services will be discussed further in Chapter 4.

### **Committee view**

3.65 This chapter has outlined the inappropriateness of residential care for young people living with disability. The committee notes that RACF are designed for older

68 NSW Council for Intellectual Disabilities, *Submission 75*, p. 1. See also: Queensland family and Child Commission, *Submission 26*, p. [2]. 'A child with a severe disability, who has been relinquished to the care of the child protection system, will on their 18th birthday be transitioned to "independence". While there is a process which prepares a child to transition to independence and even further, a level of post-care support (currently being overhauled following the Carmody Inquiry) the issue remains that there is very limited long term accommodation options available that are able to provide the young person with 24 hour support and care.'

69 Mr Gordon Trewern, Chief Executive Officer, Nulsen Disability Services, *Committee Hansard*, Perth, 17 February 2015, p. 45.

70 Ms Stephanie Gotlib, Chief Executive Officer, Children with Disability Australia, *Committee Hansard*, Melbourne, 11 March 2015, p. 27.

Australians and are not funded to provide care for young people or people with severe disability. It is the committee's view that everyone is entitled to live in a home of their choosing.

3.66 The committee recognises the importance of young people having access to a key worker early in the diagnosis of a progressive disease or disability. The key worker can assist a young person and their family navigate government departments and service providers, and avoid making uninformed decisions. The committee has been presented with evidence of key worker programs that have successfully worked. The idea of the key worker will be expanded on later in the report.

3.67 The committee is also concerned about the inadequate provision of respite services. This chapter has highlighted the value of these services and that the provision of additional funding can result in improved outcomes for both carers and young people by allowing young people to remain in the community.

3.68 The committee recognises that the mental health of young people in residential care is often exacerbated or acquired because of the emotional and psychological impacts of an environment which is not age-appropriate. It is the committee's view that there must be specific attention given to ensuring good mental health and well-being of young people in care.



# Chapter 4

## Current systems of care for young people living with severe disability

### Introduction

4.1 This chapter discusses the following terms of reference:

- (c) the health and support pathways available to young people with complex needs;
- (e) alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities; and
- (g) what Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future.

### Service delivery and transition

#### *A siloed approach*

4.2 Most of the young people who are the subject of this inquiry have a range of complex support needs.<sup>1</sup> These complex support needs can range from healthcare (including acute care, rehabilitation, primary health care), housing, on-going daily care (ranging from housekeeping tasks such as shopping to being turned in bed or showered), and access to supports (such as wheelchairs and hoists). Most of these tasks are deemed mainstream services, that is, everyone's expectation—regardless of ability or disability—is to be able to access healthcare, housing and to eat a meal in their own home. Some of these tasks are deemed specialist disability services such as access to supports and to disability support personnel. There are also other support services that cross-over between the mainstream and disability sectors such as rehabilitation and housing—including housing people with disability within the aged care sector. In their submission, Developmental Disability WA (DDWA) and People with Disability WA (PwDWA) say that:

By the very nature of their needs, young people with complex needs are more likely to be at the interface between the disability support system and mainstream supports and services.<sup>2</sup>

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1 National Complex Needs Alliance, *Submission 121*, p. 1. In its submission to the committee, the Alliance noted: 'While the experience of a single disadvantage can create difficulties for people, the experience of multiple disadvantages can have a compounding and persistent effect, reinforcing barriers to getting ahead and increasing the likelihood of other related problems later in life.'

2 Developmental Disability WA and People with Disability WA, *Submission 158*, p. 7.

4.3 Due to the complexity of their needs, one of the difficulties that young people and their families face is navigating the many different departments and agencies in order to cobble together the services that are required. DDWA and PwDWA note that 'pathways between human service systems are inherently difficult to navigate'.<sup>3</sup>

4.4 The committee received a significant amount of evidence indicating that many state, territory and Commonwealth departments operate within a silo, independent of the other agencies and departments around them.<sup>4</sup> Dr Bronwyn Morkham, National Director of the National Alliance for Young People in Nursing Homes noted that governments at all levels have not articulated a standard (or series of) pathways for all agencies to follow when seeking to place a young person in long term accommodation:

It is not just about information and the lack thereof. There is no clearly articulated pathway for anybody to go down. So health does not know about a pathway; it stops at the hospital door. Disability does or does not pick it up, and it has its particular pathway. But there is no integrated pathway for families, for clinicians, for anybody to look to, to do that with.<sup>5</sup>

4.5 Ms Sue Hodgson, a mother of a young woman, describes the 'twenty years [that] was spent working my way through a minefield of systems'.<sup>6</sup> Other witnesses describe the apparent abdication of responsibility by some agencies. For example, Daniel Everingham 'is not even eligible for funding for a wheelchair while he is in the nursing home as this is only available if he goes into a group home or lives at home'.<sup>7</sup> The perversity of this outcome is reinforced further when the logic of why he lives in a nursing home is considered:

It seems inconceivable that Daniel can be in receipt of disability services from the NSW government but denied access to essential equipment just because he is in a nursing home. The fact he is in aged care because the [NSW Government Ageing, Disability and Home Care] cannot provide a suitable housing option, which then makes him ineligible for equipment services just adds insult to injury.<sup>8</sup>

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3 Developmental Disability WA and People with Disability WA, *Submission 158*, p. 7.

4 See, for example: Ms Kirstine Bruce, *Committee Hansard*, Perth, 17 February 2015, p. 11; Mrs Gail Palmer, General Manager, MS Society WA, *Committee Hansard*, Perth, 17 February 2015, p. 19.

5 Dr Bronwyn Morkham, National Director—Young People in Nursing Homes national Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 27.

6 Ms Sue Hodgson, *Submission 112*, p. 2. See, for example: Mrs Michelle Newman, HACC Transition Program Manager, Aged and Community Services Australia, *Committee Hansard*, Sydney, 19 February 2015, pp 20–21. 'People within the system find it difficult to navigate, so for people outside of the system I think it is even more complicated and more complex. Those who do not have family or friends that are able to do that for them absolutely fall through the cracks.'

7 Mrs Sue Everingham, *Submission 111*, p. [2].

8 Ms Nicole Everingham, *Submission 111*, p. [2]. See, for example: YoungCare, *Submission 154*, p. 17.

This example aptly illustrates how a young person requiring multiple services can slip through the cracks.<sup>9</sup> There seems to be limited or no co-ordinated approach between the departments and agencies—housing, disability services, the National Disability Insurance Agency (NDIA)—that offer relevant services for Mr Everingham to ensure that he receives an acceptable service outcome—his own wheelchair.

4.6 Dr Morkham elaborated on how different departments abdicate their responsibility to the individual:

So when the NDIS [National Disability Insurance Scheme] looks to Health and says, 'Here is someone with a health need—Health, you deal with it,' Health says, 'Hang on a minute—we have a very limited budget, we are overwhelmed already, we are under-resourced; we don't have anything to offer you; back to you, baby.' Back over it goes to the NDIS, who then says, 'But Health, you are legislatively responsible for this: you step up.' We have this butting of heads again. We continue to go round in that circle...<sup>10</sup>

Ms Lyn Morgain, Chair of the National Complex Needs Alliance, explained that this occurs due to the 'jurisdictional push-pull between levels of government':

Once somebody is in a particular facility funded by a certain level of government with a certain scope of responsibility, there can be a reticence on the part of another level of government to provide much-required supplementary support. That is your first level of responsibility shifting—the 'blame game', if you like.<sup>11</sup>

4.7 In their submission, Developmental Disability WA and People with Disabilities WA went further describing each department or service system as 'gatekeepers':

Each service system is effectively designed to 'gate keep' access to it and each system is primarily focussed on addressing the needs that specifically relate to its particular focus and trying to distinguish between different needs within the same individual person. This is profoundly obvious in the experience of young people with disabilities who have complex needs who by the nature of their needs tend to need to access multiple service systems and who as a consequence of their complex needs tend to experience significant challenges in navigating these systems independently.<sup>12</sup>

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9 See, for example: Ms Carol Bennett, National Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, Sydney, 19 February 2015, pp 14–15. "We know that people with dementia fall between the cracks of aged care and disability services'. Mrs Natasha Chadwick, Managing Director, Synovum Care Group, appearing on behalf of Leading Age Services Australia, *Committee Hansard*, Sydney, 19 February 2015, p. 20. Create Foundation, *Submission 80*. Create notes the lack of coordination between the disability and child protection sectors.

10 Dr Bronwyn Morkham, National Director—Young People in Nursing Homes National Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 25.

11 Ms Lyn Morgain, Chair, National Complex Needs Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 5.

12 Developmental Disability WA & People with Disabilities WA, *Submission 158*, p. 7.

4.8 One family spelt out what this lack of support translates into for an individual:

My experience with [the Victorian Department of Human Services] was really disappointing. I spent hours on the phone just to be told there was nowhere except RAC[F] for Emily. I contacted Mary Wooldridge, the minister for disability services, via a radio program. She passed me onto her representative who took three weeks to get back to me. This representative passed me onto yet another representative. I finally received a phone call from the latest representative while collecting my grandchildren from school. The representative cemented their stance that there was "nothing" for Emily. I felt disgusted and angry and I noticed that everyone in the schoolyard had turned around to look at me. All I remember saying was "How can it be that there was nothing 16 years ago and there is still nothing now? Why is there nothing?" The next day I received a twelve page document with nothing but RAC[F] facilities for Emily. Emily is now living in RAC[F] where she doesn't want to be.<sup>13</sup>

4.9 Within some state governments, there is an apparent disconnect between what the relevant disability agency believes is being delivered and what clients actually perceive as being delivered on the ground. Dr Ron Chalmers, Director-General of the Western Australian (WA) Disability Services Commission (DSC), stated that WA is providing information and support to young people:

Through a whole range of processes, including the statewide local area coordination [LAC] system and now the rollout of NDIS My Way, the focus is on not just giving people a list of where the different houses are around the state, which I think might be useful for some, but I think, more importantly, having confidence that people who are seeking a particular style of support arrangement get good quality information about the range of those services and supports...

A local area coordinator employed by the Disability Services Commission regularly liaises with social workers in that hospital setting.<sup>14</sup>

4.10 This in stark contrast to evidence received in the same hearing from non-government service providers:

[S]o there are some LACs who have extremely good relationships with families, who know exactly what is available in their area and who can point families towards organisations. Then I have come across families in

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13 Name withheld, *Submission 41*, p. [2]. See also: Name withheld, *Submission 97*, p. 1. An intellectually disabled young man was allowed to leave a hospital after treatment with no communication with parents or other providers in the system to ensure he would be safe. There needs to be a 'handover' to another provider in the system.

14 Dr Ron Chalmers, Director-General, WA Disability Services Commission, *Committee Hansard*, Perth, 17 February 2015, p. 31.

the community who were not even aware of what an LAC is, or where they should go and what they should do.<sup>15</sup>

4.11 Improved co-operation and linkages between the silos of service delivery is crucial. In the discussion paper, *Cross sector service co-ordination for people with high and complex needs: Harnessing existing evidence and knowledge*, cross sector co-ordination is noted as being:

[A] critical scheme design element to ensure that NDIS participants get the range of services and supports they need to pursue their goals and participate in society and the economy. Any failure of other sectors to provide access to quality services will increase the costs of disability support and risk the sustainability of the NDIS. Coordination can thus also be seen as a way of addressing this fundamental risk facing the NDIS. For these reasons cross-sector coordination should be a core element in NDIS design.<sup>16</sup>

Cross sector service should include the following elements:

- high level inter-sectoral collaborative agreements and related infrastructure (macro level) so that system barriers do not undermine NDIS aims;
- coordinators actively negotiating between sectors and services to ensure people obtain the necessary supports: a range of local and cross-sectoral mechanisms enable coordination activities; and
- agreed goals focussed on outcomes for people, including social and economic participation.<sup>17</sup>

4.12 The next sections will explore how young people access services within each of the silos—primary and allied healthcare, aged care, disability and housing—and the current transition process.

### **Health**

4.13 Many, but not all, young people described in this report begin their journey with disability in the healthcare system. The previous chapter highlighted how an informed transition with adequate supports results in more sustainable and higher

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15 Mrs Caroline Watt, Executive Director, Operations, Nulsen Disability Services, *Committee Hansard*, Perth, 17 February 2015, p. 40. See also: Ms Tracy Foulds, Executive Officer, Headwest, *Committee Hansard*, Perth, 17 February 2015, p. 9.

16 Centre for Disability Research and Policy, University of Sydney (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA) 2014. *Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge*, p. 1, <http://sydney.edu.au/health-sciences/cdrp/discussion-paper-complexneeds-july2014.pdf> (accessed 25 May 2015).

17 Centre for Disability Research and Policy, University of Sydney (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA) 2014. *Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge*, p. 2, <http://sydney.edu.au/health-sciences/cdrp/discussion-paper-complexneeds-july2014.pdf> (accessed 25 May 2015).

quality outcomes for young people including living where they want to live and living their life in a way that matches their capability and ambition. This section will focus on the reasons that many young people migrate directly from the health system to the aged care sector.

4.14 Mrs Fiona May of the ACT Disability, Aged and Carer Advocacy Service argued that the primary driver for the health system to move individuals occupying hospital beds—specifically acute care beds—is cost. The health system views young people with disability living in a hospital as 'bed-blockers' and as such seeks to move that young person elsewhere to free up the bed. Mrs May added:

There is one other thing I would like to add to that, and it is about people who are in the hospital system and on the fast-track pathway to nursing home care. What we know is that, for people who have a catastrophic injury, a stroke or another event that pushes them into hospital, once their health issue is to an extent stabilised the hospital system is incredibly keen to move them out of the hospital bed. The hospitals call them 'bed blockers'. The hospital system puts a lot of pressure on the social workers within hospitals to find alternative places for people to go, and generally nursing homes are the only open door. So we find that we are doing quite a lot of advocacy in that setting to stop people from being pushed into a nursing home.<sup>18</sup>

4.15 The committee received evidence that young people end up staying longer than they should in the acute care system due to a lack of options:

The bed blockages in the rehabilitation services (or downstream blockages) mean that pressure starts to build up in acute hospitals to the extent that the next wave of people with ABI [acquired brain injury] have nowhere to go once the acute phase of their care has passed.<sup>19</sup>

4.16 The Office of the Public Advocate (Queensland) noted that 'it does not make good economic sense to care for people in acute hospital beds, for example, when the same person could be receiving more appropriate support in a community based setting at a significantly reduced cost'.<sup>20</sup> The Victorian Department of Health and Human Services defines the actual cost in an acute ward at between \$473 and \$824 per bed day (\$172 645–\$300 760 per annum).<sup>21</sup> This compares with a cost of

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18 Mrs Fiona May, CEO, ACT Disability, Aged and Carer Advocacy Service, *Committee Hansard*, Canberra, 15 May 2015, p. 27.

19 Office of the Public Guardian (Queensland), *Submission 134*, p. 8.

20 Office of the Public Advocate Queensland, *Submission 134*, p. 2. See also: Mrs Marian Dalrymple, Manager, Wesley Neurological Support Services, Wesley Mission, *Committee Hansard*, Melbourne, 11 March 2015, p. 4.

21 Victorian Government Health Information, *Fees and Charges for Acute Health Services in Victoria*, November 2014, <http://health.vic.gov.au/feesman/fees1.htm> (accessed 26 May 2015). This is in a shared ward.

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approximately \$70 000 per annum for an aged care bed.<sup>22</sup> Although these costs are directly borne by different levels of government—state governments pay for hospitals and the Commonwealth pays for aged care—it is salient to note that the cost of providing care in hospitals is more than aged care.<sup>23</sup> In turn, the provision of aged care costs more than providing similar services in the community.

4.17 Every example is different; however, Table 4.1 below compares two similar cases assessed by the Office of the Public Advocate (Queensland)—one remained in the acute system, the other began to receive rehabilitation support at the optimum time—and gives a sense of proportion to the costs imposed on a congested acute system. For case study 1, the cost to both the individual and the system is significant. Case study 1 remains in the acute system, not receiving any rehabilitation services at a total cost of \$1 200 per day, whereas case study 2 is living in the community and receiving rehabilitation support at one third of that cost.

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22 See: Mr Russell de Burgh, Branch Manager, Policy and Evaluation Branch, *Committee Hansard*, Canberra, 15 May 2015, p. 41. Mr de Burgh told the committee that a facility can charge a basic daily fee of 85 per cent of the single rate of the aged pension or \$47.49 per day. This contribution is on top of the Commonwealth funded contribution of \$56 000 per person living in residential care.

23 This in turn is another driver whereby the cost of caring for that individual is shifted from the state's ledger to the Commonwealth's.

**Table 4.1: Estimated costs of delayed transitions through the rehabilitation continuum**

Phase of Care	Case Study 1 - Client with severe head injury	Case Study 2 - Client with severe complex head injury
Compensation	None	Awarded
Acute in-patient admission	34 days @\$1,200 per day \$40,800	266 days @\$ 1,200 per day \$319,200
Sub-acute in-patient rehabilitation	694 days @ \$1,200 per day \$832,800	241 days @ \$1,200 per day \$289,200
Delay to next phase of care	412 days	Nil – funded by Workcover
Community-based accommodation and rehabilitation	Not applicable awaiting supported accommodation	Ongoing case management 6-7 sessions of community-based therapy per week @ \$158 per hour 24/7 in-home care program – Approx \$5,200 per week
Estimated additional costs related to delay to community	\$325,000 over 412 days	Nil
Summary	Currently waiting for 412 days in sub acute hospital bed for transition to community and rehabilitation Cost: approx \$1,200 per day	Currently in supported accommodation receiving weekly therapy and 24/7 support and case management Cost: approx \$486-\$885 per day

Source: Office of the Public Guardian (Queensland), *Submission 134*, p. 8. Quarterly Brain Injury Services Meeting (QBISM) Group, *A Comprehensive Service System for Queenslanders with Brain Injury, Positioning Paper* (August 2013).

4.18 In its submission, Headwest stated that a lack of appropriate facilities leads to young people with disability being moved from the health system into residential aged care facilities (RACF):

The health and hospital systems in WA are unable to accommodate individuals indefinitely while waiting for a suitable alternative to become available. Lack of appropriate and timely access to rehabilitation and transitional services puts additional stress on an already stretched system. This further increases the pressure to discharge young people as quickly as possible. In this environment, the only option often available is through the aged care sector...

In WA, there are few hospital based rehabilitation and transitional services and even fewer non-hospital services such as provided by Brightwater Care Group.<sup>24</sup>

4.19 The committee also heard that many 'people with ABI, while waiting for appropriate rehabilitation services, spend their time in acute hospital beds, without receiving the important rehabilitation they need'.<sup>25</sup> The committee received evidence from Alfred Health indicating that if dedicated resources made available to young people whilst in the health system—from injury to discharge and as they transition away from the health system—can make a substantial difference to whether that

24 Headwest, *Submission 103*, p. 4.

25 Office of the Public Advocate Queensland, *Submission 134*, p. 6. See also: *Submission 31*, p. [2]. Gordon noted that 'after some time in hospital, I found myself living in a nursing home'.

person ends up in RACF or in other accommodation. Alfred Health works at the interface between the health system and the community to ensure adequate and appropriate rehabilitation services are provided to optimise the transition process.<sup>26</sup>

4.20 Mrs Janet Wagland of the Brightwater Care Group noted the need for greater communication and co-ordination between different departments at the state level:

Really what should happen is that there should be a closer connection between the hospital system and the Disability Services Commission or the disability system that is relevant in every state. There is a very large disconnect between both, and many of the people we see who have a newly acquired disability—and often a very complex newly acquired disability—have no understanding of any disability system. They have never been connected with it, and before they know it they have an ACAT and are in a nursing home. They do not even know how to apply to the Disability Services Commission. Their families do not understand. The hospital system is such a fast-track system by necessity—because it is around people who are acutely unwell—that they cannot keep people in their beds for too long; otherwise, there are no places for others.<sup>27</sup>

4.21 At its Melbourne public hearing, the committee received evidence about a successful Canadian scheme—Alberta Assessment and Placement Instrument—which utilises a 'nationwide assessment and placement protocol for young people deemed to be at immediate risk of aged care placement', which 'enables the most appropriate rather than the most immediately convenient recommendation for accommodation placement'.<sup>28</sup> This type of scheme will be discussed in later chapters.

#### *Committee view*

4.22 Evidence to the committee suggests that there are many young people presenting to the health system with an ABI or TBI. In some cases, these young people and their families have no previous experiences with disability or the disability sector and, as such, are in many respects guided almost entirely by the health professionals within the acute system. Current decision making processes around transition from acute care to other options including aged care are poorly informed. The committee is concerned that young people, with little knowledge of other accommodation or transition options are being moved into aged care. The committee is also concerned that the health system itself is not aware of other accommodation or transition options and is operating in a silo removed from other government agencies and service providers such as disability and housing. It is the committee's view that a more comprehensive assessment tool, such as the Alberta Assessment and Placement

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26 Alfred Health, *Submission 137*.

27 Mrs Janet Wagland, Manager—Services for Young People, Brightwater Care Group Inc, *Committee Hansard*, Perth, 17 February 2015, p. 2.

28 Ms Deborah Farrell, Senior Manager, NDIS Futures, Multiple Sclerosis Limited, *Committee Hansard*, Melbourne, 11 March 2015, p. 31. This scheme is the Alberta Assessment and Placement Instrument which 'enable health professionals to conduct a comprehensive, validated, consistent and rigorous evaluation of client care and accommodation needs.

Instrument needs to be established and utilised in the health system. This will ensure that the support and accommodation requirements in the short and longer term—including the likely journey of transition and placement—are clearly identified and understood by young people, their families, and state and Commonwealth Governments.

4.23 The next section will examine the role of support services both in the health and aged care sectors.

### ***Rehabilitation and other health support services***

4.24 The lack of access and the inadequacy of rehabilitation services in hospitals and RACF is highlighted in Chapter 3. Many submitters and witnesses discussed the importance of rehabilitation in helping young people with severe disabilities regain independence. In its submission, Leading Age Services Australia (LASA) raises the concept of 'reablement' rather than rehabilitation, stating that this is:

[G]enerally focused on short-term, targeted intervention and is about bringing a person to their full potential, to accommodate their illness by learning or re-learning the skills necessary for daily living...

Further, LASA notes that this is difficult to fit within the RACF model:

[RACF] currently follows a medical model, and is geared to support the resident with the illness and frailty they live with, not to rehabilitate to a pre-existing level of fitness.<sup>29</sup>

4.25 Mrs Helen Barker, mother of Angela, said that 'rehabilitation is the most important thing'<sup>30</sup> and that poor access to rehabilitation shortly after acquiring or developing a disease or disability resulted in delaying a young persons' pathway to independence or reaching independence at all.<sup>31</sup> One witness described the despair that some young people feel having made substantial progress with rehabilitation in hospital only to suffer a fall and be told they will be moved into RACF with little or no access to rehabilitation.<sup>32</sup>

4.26 The committee received evidence describing the importance of integrated slow stream rehabilitation programs to some people. Slow stream rehabilitation is a specialist program designed for those who are likely to have longer term and more

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29 Leading Age Services Australia, *Submission 43*, p. 3.

30 Mr Terry and Darryl Bainbridge, *Submission 71*, p. [3].

31 Mrs Helen Barker, *Submission 74*, p. 2. 'If Angela had been given the appropriate care, accommodation and rehabilitation in the early days, we believe she would have achieved these milestones much earlier and may not have needed as much care and supervision.'

32 Mrs Gail Palmer, Manager—Community Programs, MS Society WA, *Committee Hansard*, Perth, 17 February 2015, p. 13. See also: Mr and Mrs Kev and Lyn Isaacs, *Submission 86*, p. [1]. Paul Issacs was discharged from a rehabilitation centre as 'he was not making enough progress to be retained as in-patient', receiving no rehabilitation living at home with his parents.

complex rehabilitation needs yielding incremental progress.<sup>33</sup> Mr Peter Bewart of The Salvation Army noted:

We also advocate that step-down units attached to hospitals and transitional living services that provide slow stream rehabilitation are critical within this area of care need. These services would give young people at risk of admission to residential aged care the time and services they require to recover and maximise their abilities in activities of daily living, thereby decreasing the dependence on the service system. Indeed, traditionally, aged care has not had a rehabilitation culture, focusing on supporting people with limited capacity and often unable to meet the complex social and rehabilitative needs of younger people.<sup>34</sup>

4.27 Further, Ms Lyn Morgain of the National Complex Needs Alliance noted the Alliance's 'concern about the inadequacy of funding' for this type of rehabilitation and asked which agency would accept funding responsibility with the introduction of the NDIS.<sup>35</sup>

4.28 Despite the lack of funding, there are some good examples of slow stream rehabilitation working in a range of settings. Brightwater Care Group (BCG), a Western Australian based aged care provider, operates a range of rehabilitation programs specifically for young people with severe disabilities. These include:

- additional Care Subsidy Scheme—additional services within RACF;
- Long Stay Younger Person Program—'transitional support and interim accommodation for people with complex disability unable to discharge from the metropolitan hospital system'; and
- Oats St Rehabilitation Program—'a residential and community based rehabilitation program for people with a diagnosis of neurological disability, due to ABI. The program has a strong focus on Cognitive Rehabilitation Therapy and goal directed individualised outcomes'.

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33 For example, traditional rehabilitation may relate to a supported recovery from a physical injury, such as a broken leg or arm, in the absence of any other co-morbidities, whereas slow stream is more appropriate for those who have a combination of factors leading to a likely slower recovery due to cognitive and physical (movement) constraints.

34 Mr Peter Bewert, Executive Manager, Care Services, The Salvation Army, *Committee Hansard*, Canberra, 15 May 2015, p. 2.

35 Ms Lyn Morgain, Chair, National Complex Needs Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 4.

- Endeavour House—'shared supported living in a high care environment conducive to supporting people with brain injury who have extremely complex care and health needs'<sup>36</sup>

4.29 In their submission, Greystanes Disability Services described the mobile health team they operate in the Blue Mountains region of NSW, with expertise in supporting people with intellectual disability, consisting of nurses, a physiotherapist and a dietician. This support is provided to people in their home. Greystanes focuses on Person Centred Active Support (PCAS) 'as the framework for how staff work with and assist the people they support.' Further:

Research has demonstrated that people with severe intellectual disability can spend eighty percent or more of their daily awake hours disengaged and not involved in any meaningful activity and that disengagement is a leading cause of challenging behaviour. PCAS is about the skills and capacity of staff and the service in enabling engagement of the person with a disability in meaningful activities and relationships. This is an evidence based approach that focuses on ensuring people, no matter their level of intellectual disability, spend their time engaged in meaningful activities and relationships and experience choice and control as valued members of the community.<sup>37</sup>

#### *Committee view*

4.30 Rehabilitation should not be seen as a generic static service; it should be a dynamic service reflecting an individual's capacity, ambition and the nature of their disability. It should be delivered as an evolving holistic service focusing on the fundamentals initially—such as prevention of contractures, continence training, speech pathology (communication and swallowing)—with the ultimate objective being to facilitate socialisation and reintegration of the young person into the community in a way that they feel valued and can contribute according to their capacity.<sup>38</sup>

#### *Aged Care*

4.31 The role of the health system in transitioning young people with disability to the aged care sector as a default option has been considered in the previous section. This section will examine the role of the Aged Care Assessment Teams in facilitating that transition and also some of the obstacles for those seeking to transition from RACF to other forms of accommodation.

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36 Brightwater Care Group, *Submission 115*, pp 1–2. See, for example: South Australian Government, *Submission 157*, p. [6]. The South Australian Government, in its submission explains how its fourth generation rehabilitation services 'can help people living with a disability reach their rehabilitation goals through access to a range of integrated rehabilitation services'. These services are available through supported disability accommodation, SA Health Hospital Rehabilitation Services and the Brain Injury Rehabilitation Unit.

37 Greystanes Disability Services, *Submission 17*, p. [2].

38 See: Mrs Keryn Hickey, *Submission 106*, p. [2].

### *Aged Care Assessment Teams*

4.32 An assessment from an Aged Care Assessment Team (ACAT) must be undertaken prior to a person of any age being granted funding for short stay (respite care), transition care and longer or permanent positions in RACF.<sup>39</sup> For those aged under 65, ACAT must contact the state or territory government and be 'satisfied that there is no other alternative' before recommending a RACF placement.<sup>40</sup> Graham Prior, CEO of Hall & Prior, described ACAT as the gatekeepers of the system ensuring that 'people in need are identified and placed appropriately in care, in community, in mental health or into aged care':

These people are the eyes and ears out in the community, working with doctor's surgeries, working with social workers and they are very, very skilled and very focused on finding pathways for most people in care today in Australia.<sup>41</sup>

4.33 In theory, the ACAT process ensures that no young person is inappropriately transferred to live in RACF if other community options are available. Although this works in some cases, the committee has received evidence suggesting that this process is not a failsafe. Mrs Rosenthal of the Salvation Army agreed with Mr Prior's assessment of ACAT, however, noted that changes to the Commonwealth Home Support Program has resulted in the loss of complex case management services. The loss of these services decrease the likelihood that a young person with complex needs will successfully transition to live in the community.<sup>42</sup>

4.34 In WA, Ms Laurence of the Brightwater Care Group noted that despite the ACAT process it is possible that 'there is no actual registration within the Disability Services Commission that that person has been given an ACAT or in fact that they exist'. The young person is moved into RACF 'without any ongoing follow-up or any ability to apply for funding unless somebody within the aged-care facility then follows through that more formal process'.<sup>43</sup> It is not clear whether or not there is a requirement to review the initial ACAT recommendation either at a fixed interval or when an individual's circumstances change.

4.35 The committee notes that despite its shortcomings, ACAT fulfils a gatekeeping process and with further refinement may prove to be integral in diverting

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39 See: Australian Government Department of Social Services, *ACAT Assessments*, <http://www.myagedcare.gov.au/eligibility-and-assessment/acad-assessments> (accessed 19 May 2015). The ACAT teams are funded by the Commonwealth and operated by state governments.

40 Mr Russell De Burgh, Branch Manager, Policy Branch, Aged Care Policy and Reform Group, Ageing and Aged Care Services, Department of Social Services, *Committee Hansard*, Canberra, 15 May 2015, p. 46.

41 Mr Graham Prior, CEO, Hall & Prior, *Committee Hansard*, Canberra, 15 May 2015, p. 6.

42 Mrs Nicola Rosenthal, Business Development and Community Services Manager, The Salvation Army, *Committee Hansard*, Canberra, 15 May 2015, p. 6.

43 Mrs Janet Wagland, Manager—Services for Young People, Brightwater Care Group Inc, *Committee Hansard*, Perth, 17 February 2015, p. 1.

new admissions of young people into aged care. This will be discussed further in chapter 6.

### *Transition from RACF*

4.36 The committee has received a range of evidence outlining the impediments for young people seeking to transition from RACF to other forms of accommodation. The previous section has discussed the role of rehabilitation and other services, highlighting that the absence of appropriate access to support hampers the ability for young people to maintain or regain their independence.

4.37 The committee received evidence that described many young people developing a learned dependency by living in a RACF. This loss or lack of independent living skills for young people with complex disabilities can often prove decisive in determining whether a young person lives independently or in a RACF. Ms Vicki Wilkinson shared her experience when moving from a RACF to the community:

It was an hour by hour, minute by minute experience. The idea of living a normal life in the community was just so far away. It was still so foreign. It is like you know that normalcy is somewhere there just beyond your fingertips. You can almost smell, taste, and feel it, but you just can't manage to get a grasp of it. It is like you are searching around in the dark for the right steps, the right levers to get you to where you know you should be and could be.

It really is like you are groping aimlessly in the dark, every lead of potential information you grasp for dear life..... because there is no manual to guide your transition from a high care, institutional nursing home, back into the community.

There is not a How to Guide in community reintegration!<sup>44</sup>

4.38 Often the ability to live independently hinges on quite fundamental aspects of living:

I have come to realise there were things that I took for granted in the nursing home, now I'm out, without regular care, I have realised that really I have no idea.

Who do you call when your catheter comes out? Who do you ring? Who can you rely on?

A basic continent aid, can be the undoing of you. In the nursing home I didn't need to know what size catheter I used, where to get it from nor how to use it. It always just arrived when I needed it. This institutionalisation of myself has led me to being unknowledgeable and ill-equipped in the community. My lack of knowledge on my own simple necessities now creates a barrier between people that can assist me. I can't tell them exactly what it is that I need.<sup>45</sup>

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44 Ms Vicki Wilkinson, *Submission 107*, pp [4–5].

45 Ms Vicki Wilkinson, *Submission 107*, p. [5].

4.39 Terry Bainbridge currently lives in a nursing home, but spends up to 4 nights a week at home living with his brother. Mr Bainbridge is able to do this through funding of support services which provide 5 hours of support per week—1 hour of speech pathology, 2 hours of physiotherapy, and 2 hours of occupational therapy. With some additional support services funded through his individual support package, he could live at home fulltime:

The barrier to getting him home is getting his ISP funded, we were told that getting him home would save the Government around half a million dollars. When he does come home he will save money. At the moment he is paying \$1450 per month for aged care fees. If he was at home he would pay about \$1000 a month for rent food and bills.<sup>46</sup>

4.40 The committee also received evidence that RACFs should be viewed as a valid transition option when there are genuinely no other options available. However, this transition should only be engaged with clear entry and exit provisions (detailed in a care plan) for young people. MS Australia recommends that:

We need to create articulated pathways of care to delay young people from entering residential care prematurely. Where appropriate move young people currently residing in nursing homes into age-appropriate accommodation. [We need to] provide support to young people who remain in aged care settings to facilitate enhanced recreational, social and community participation.<sup>47</sup>

4.41 Positive stories of successful transitions to independent living from RACF were also heard by the committee. Mr Ben Thompson moved into a YPIRAC funded shared supported accommodation after living in a RACF for three years. He has access to support services such as physiotherapy and speech pathology, and is supported by a key worker who helps co-ordinate his care. Mr Thompson has noted substantial improvements since then:

I see my physio three times a week. I was getting physio just two times a week in the nursing home. I am so motivated with my rehab. I have begun walking with a frame and I can now walk in the pool. It feels tremendous. I would do physio everyday of the week if I could. I would also do more speech therapy; I currently see my speech therapist once a week. I am re-learning to speak. It's so much better to communicate now, not such a long process. It makes me feel normal now that I can communicate by talking. When I moved out of the nursing home, I stopped being Peg-fed and was able to eat again too!<sup>48</sup>

4.42 As discussed earlier in this chapter failures within the service system can lead to family playing a decisive role in determining the success or failure of transition. Ms Lauren Bellert's husband, Michael, moved from a RACF to a shared supported

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46 Mr Terry Bainbridge and Mr Darryl Bainbridge, *Submission 71*, p. 4.

47 MS Australia, *Submission 46*, p. 5.

48 Mr Ben Thompson, *Submission 52*, pp [1–2].

accommodation late last year. Michael's doctor described Ms Bellert as 'tenacious' and integral to this transition:

Without me, visiting [Michael] with [our daughters], fighting for his rights and assisting him with regular physio with outside specialists Michael would not have come as far as he has or continue to make progress. The system tries to fit everyone into neat boxes but the reality for every situation is different and needs to be assessed accordingly. I noticed improvement in the first week of Michael leaving the nursing home, which makes me wonder how far he may have come, if only he was transferred there from the beginning.<sup>49</sup>

### *Committee view*

4.43 In noting the important role ACAT plays as the gatekeeper to every person admitted to RACF, it is the committee's view that the ACAT process needs to be refined to ensure that if aged care is used, it is only used as a transition after a clear entry and exit plan is put in place. In order for transition to be a realistic objective, it is imperative that young people are able to remain independent, have access to allied health services—such as speech pathology and rehabilitation, and access to a key worker to help facilitate the process. It is the committee's view that the key worker should be engaged prior to the young person entering aged care as this will ensure that an informed decisions will be made. Key workers will be discussed later in this chapter and in Chapter 5.

### *Housing*

4.44 Lack of suitable housing is a key constraint for young people seeking to transition from the health and aged care systems. In its submission, National Disability Services noted that 'demand for specialist disability accommodation exceeds supply' and that it should be a priority to 'improve access to housing options that are affordable and provide security of tenure.'<sup>50</sup> Mrs Nicola Rosenthal of The Salvation Army went further saying that the provision of service is futile if accommodation options are not available for young people.

We can slow-stream-rehab people as long as we like, but, if there is nowhere to go, there is nowhere to go.<sup>51</sup>

4.45 Security of tenure is important if young people are to use part of an ISP to build access and mobility supports within a house or unit.

4.46 Some submitters noted that mainstream public housing should be made more available for young people as this would help free up specialist disability housing for those most in need.<sup>52</sup> Focus ACT raised the impact of housing affordability on

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49 Ms Lauren Bellert, *Submission 44*, pp 5–6.

50 National Disability Services, *Submission 90*, p. [2].

51 Mrs Nicola Rosenthal, Business Development and Community Services Manager, The Salvation Army, Aged Care Plus,

52 See: National Disability Services, *Submission 90*, p. [2]; Mrs Helen Barker, *Submission 74*, p. [2].

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housing options for young people seeking to move from or avoid being placed in a RACF.<sup>53</sup>

#### *Public housing waitlists*

4.47 There are other factors that challenge young people seeking to live in the community. One submitter, Ms Sam Petersen, related her story about being hospitalised and receiving rehabilitation after suffering a stroke. Ms Petersen was in hospital and rehabilitation for a period of five months. During this time she was forced to give up her public housing unit. After recovering to a state where she could return to independent living, she has instead been forced to move into a RACF until public housing becomes available again. This has led to Ms Petersen receiving less support services and feeling very uncertain about her future.<sup>54</sup> The committee is concerned about the apparent low priority given to those with severe disability on public housing waiting lists.

#### *Integrating housing and support services*

4.48 Integrating housing and supports reflects the movement of disability policy from a nursing model to one of person-centred support under the NDIS. The key to person-centred support provision revolves around accessible housing and adequate in-home support.<sup>55</sup> Australian Home Care Services noted that 'appropriate supports and appropriate capital to provide suitable housing options result in many people report[ing] improved life experiences'.<sup>56</sup>

4.49 The committee received evidence about the Combined Application Process (CAP) administered by the Western Australia Disability Services Commission (DSC). CAP funding, if approved, can be used to fund support services and accommodation. Mrs Gail Palmer noted that 90 per cent of those who apply for funding are not approved. Further, Ms Palmer noted the process for those with progressive and degenerative illnesses:

It was noted many years ago now—about six years ago—that for a certain group of people who were rapidly deteriorating the process was inadequate and unfair. They would be developing a disease such as motor neurone disease, be rapidly deteriorating and would put in an application to the commission. Perhaps they would be knocked back the first time and the second time. By the third time they may be accepted, but by then their

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53 Focus ACT, *Submission 45*, p. 2.

54 Ms Sam Petersen, *Submission 27*, p. [1]. See also: Ms June Reimer, Deputy Director, First Peoples Disability Network, *Committee Hansard*, Sydney, 19 February 2015, p. 5.

55 People with Disability Australia, *Submission 147*, pp 4–5.

56 Australian Home Care Services, *Submission 94*, p. 1. See also: Visionary Design Development, *Submission 95*, p. 3. This submission argues that 'the inability of the built environment to satisfy the accessibility needs of people with disabilities, thereby creating major barriers, is seldom recognised'. This submission describes the benefits of using Universal Design, 'a design approach that advocates for holistic environments able to be accessed, understood and used to the greatest degree possible by all people regardless of their age, size, ability or disability'.

needs were so critical that they had already entered a nursing home or even died from their condition. The family was destroyed by having to care for them.<sup>57</sup>

4.50 For those who are successful in obtaining funding, access to supports and accommodation services is not necessarily any easier. Ms Kirstine Bruce lodged a funding CAP on behalf of her daughter, Ms Ariana Pila. This application was successful, however, Ms Bruce pointed out that no support was provided to link Ms Bruce and her daughter with a service provider and that Ms Pila has been unable to find accommodation:<sup>58</sup>

**Ms Bruce:** Yes, they have been to see us. We have got—what is it called?

**Ms Foulds:** The CAP funding.

**Ms Bruce:** Yes, the CAP funding. So now it is just sitting and waiting for somewhere for her to go, whether it be Rocky Bay or Nulsen or whether it becomes home.

**Senator Reynolds:** Have they left that up to you, or what is your understanding of the process? You have the potential for funding, but has anyone explained to you what the process is from here?

**Ms Bruce:** Basically, we have just applied for government housing, and now we just sit and wait until something comes up in the meantime.

**Senator Reynolds:** Is Brightwater actively looking for somewhere for her to go where she can get accommodation or rehabilitation?

**Ms Bruce:** Not that I know of.

**Senator Reynolds:** And the Disability Services Commission is not doing that either?

**Ms Bruce:** Not that I know of.

**Senator Reynolds:** So you have got to a certain point there with them.

**Ms Bruce:** And it is on a standstill, yes.<sup>59</sup>

The committee notes the need for improved linkages between individuals and providers.

4.51 The different needs of young people are not just measured at one point in time, but should be measured across a lifetime. A person's continuum of care or care requirements over a lifetime reflects a person's age and their disability or disease. Just as care and support requirements will change over time, so will the type of accommodation a young person will want to live in during these different life stages.

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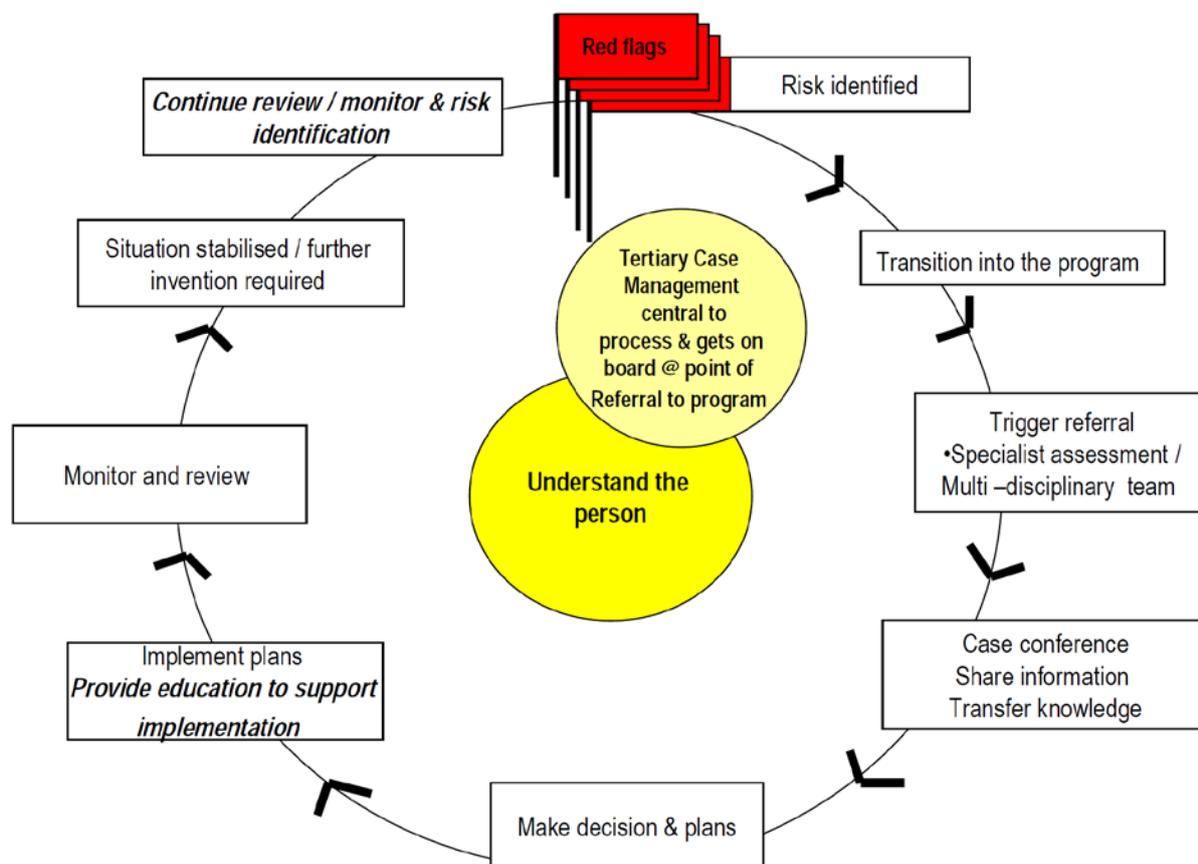
57 Mrs Gail Palmer, Manager, Community Programs, Multiple Sclerosis Society WA, *Committee Hansard*, Perth, 17 February 2015, p. 13.

58 Ms Kirstine Bruce, *Committee Hansard*, Perth, 17 February 2015, pp 11–12.

59 *Committee Hansard*, Perth, 17 February 2015, pp 11–12.

4.52 The Continuous Care Pilot, undertaken by MS Australia and Calvary Health Care Bethlehem, was a scheme that sought to recognise the 'continuum of care' operating from 2008–2010. This pilot targeted young people with chronic progressive neurological diseases who were at risk of entering RACF. This pilot sought to 'work collaboratively and in partnership across service areas in health, disability, aged care and community services; and utilises a proactive, preventative approach to service interventions that ensures existing resources are used in a timely and more effective manner than may be possible otherwise'.<sup>60</sup> The committee notes that continuous care does not end once a placement is found, instead there is an ongoing process of assessment and review with a full understanding of the particular risks a person may have. Accommodation is a critical component of continuous care. Figure 4.1 below illustrates the model.

**Figure 4.1: Model of continuous care**



Source: MS Australia, *Submission 65c*, p. 29.

4.53 MS Australia remarked on the importance of integrating housing and support services:

Young people with progressive neurological disease such as multiple sclerosis need an integrated housing and support model that is tailored to

60 MS Australia, *Submission 65c*, pp 3–6.

their needs and offers access to support and health services, while keeping them connected to the community.<sup>61</sup>

4.54 The Summer Foundation noted several examples of integrated housing and support services including the Square Woodville West Project (South Australia), Cairo Southbank (Victoria), Abbotsford Housing Demonstration Project (Victoria) and the Hunter Housing Demonstration Project (NSW). The Summer Foundation described the Abbotsford Project:<sup>62</sup>

In 2013 the Summer Foundation launched its first housing demonstration project. This project has six accessible apartments for people with high support needs peppered throughout a 59 unit mixed private and social housing inner city development in Melbourne. The Summer Foundation purchased two apartments for young people at risk of or in aged care facilities. The Transport Accident Commission (TAC) clients tenant the other four accessible apartments.

This housing is centrally located, within 500 metres of a train station and shops. This maximises independence and inclusion and minimises transport costs and reliance on paid support staff. Use of home automation technology and communication technology allows tenants to alert staff of unanticipated needs for assistance. There is a small staff office that provides a hub for support staff on site 24 hours a day.

4.55 Success in this project—as measured by increased levels of home, social and economic participation—was attributed not only to the excellent location 'near accessible public transport, shops and recreation services', but to the support received from a Community Inclusion Facilitator who offered support to plan their transitions, test out new life roles and helped establish links to the community.<sup>63</sup>

*Bricks and mortar—accommodation options and funding*

4.56 Throughout the inquiry, the committee has received evidence on the suitability of accommodation for young people living with a disability. In its submission, the Youth Disability Advocacy Service has defined 13 key benchmarks or principles against which the suitability of housing and support for young people with disabilities should be measured:

1. Accessible quality housing
2. Affordable housing
3. Homeliness
4. Tenancy Rights
5. Choice of where you live and with whom you live
6. Safeguards.

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61 MS Australia, *Submission 46*, p. 5.

62 Summer Foundation, *Submission 109*, pp 75–79.

63 Summer Foundation, *Submission 109*, pp 77–78.

7. Investment in assistive technology
8. Separation of tenancy from service provision
9. Opportunity for friendships and sexual relationships
10. Community belonging
11. Choice of support staff
12. Phased steps towards living independently
13. Access to information and peer support<sup>64</sup>

4.57 There are a range of different accommodation options available for young people living with disability that are summarised in Table 4.2. Some of these options meet all or most of these 13 basic principles.

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64 Youth Disability Advocacy Service, *Submission 62*, pp 2–3.

**Table 4.2: Summary of accommodation options for young people living with disability**

Accommodation Type	Examples
Supported at home	Greystanes <sup>65</sup> ; Melba Support Services <sup>66</sup>
Independent supported accommodation	Freedom Housing <sup>67</sup>
Intentional Communities	L'Arche <sup>68</sup> ; Rowallan Park <sup>69</sup>
Supported accommodation	Royal Rehab <sup>70</sup> ; HOPE Inc <sup>71</sup>
Hospital and Extended Care	Quadriplegic Centre
Residential Aged Care Facilities (targeted)	Mt St Vincent Home <sup>72</sup>

4.58 The last two of these options in Table 4.2—hospital and extended care, and RACF—are only appropriate as transition options (with clear entry and exit provisions detailed in a care plan) or where the young person has made a conscious decision that these arrangements are best suited to their circumstances. For example, a young person may choose to live in a Quadriplegic centre for access to rehabilitation options with the goal of becoming independent. Similarly, a young person may choose to live

65 Greystanes Disability Services, *Submission 17*.

66 Melba Support Services, *Submission 78*.

67 See: Tabled Document, *Freedom Housing versus Traditional models of care and Accommodation for Persons with Disabilities: A structured comparative analysis evaluating the models' degree of compatibility with the relevant Objects and Principles of the NDIS Act 2013*, March 2015, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents) (accessed 2 June 2015). See also: Mr Christos Iliopoulos, CEO, Freedom Housing Pty Ltd, *Committee Hansard*, Melbourne, 11 March 2015, pp 55–56.

68 L'Arche Australia, *Submission 160*.

69 Tabled Document, *Rowallan Park Intentional Community*, March 2015, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents) (accessed 2 June 2015).

70 Mrs Delia Gray, Executive Manager, Community Services, Royal Rehab and Ms Natalie Ryan, Independent Living Co-ordinator, Royal Rehab, *Committee Hansard*, Sydney, 19 February 2015, pp 27–41.

71 Mrs Sue Hodgson, *Submission 112*.

72 Ms Yvonne Kromkamp, *Submission 84*.

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in a RACF in a wing dedicated to young people such as at the Mt St Vincent Home in Ulverstone, Tasmania.

4.59 This inquiry has also highlighted that 'younger people with disabilities are not an homogenous group':

[T]heir needs differ greatly and they have individual interests and approaches to life. If the lives of these young people are really to be enhanced as much as possible they need to have choices in regard to the way they live, and in particular their accommodation. Some young people may prefer independent living, others group homes, others supported accommodation. Developing new models of accommodation and support which link in with aged care would widen the choice for these young people and create real life communities where different generations can mix as they choose.<sup>73</sup>

4.60 It is important that housing solutions recognise the differing needs of young people. In the ACT, the Community Services Directorate has developed a Housing Options Program. This program utilises 'easily accessible Housing Options Facilitators (HOF) who assist people with disability to identify and develop housing options that best meet their individual need'. More than that, the HOFs deliver the following practical solutions that actually match young people with the accommodation that they want to live in:

- assist by providing a housing options planning service to people with disability, their families and advocates;
- assist by working in partnership with community agencies who are responsible for planning;
- provide community education about housing options for people with disability; and
- provide information tools including the housing options decision making framework.<sup>74</sup>

4.61 The committee has been presented with examples of appropriate housing models for young people with severe disability. The committee conducted a site visit to the Rowallan Park facility, south of Hobart, and met a group of young people with varying degrees of independence living together in a range of supported accommodation types (see Box 4.1).

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73 Brotherhood of St Lawrence, *Submission 59*, p. 6.

74 Occupational Therapists Australia, *Submission 146*, p. [12].

#### **Box 4.1: Rowallan Park Intentional Community (Uniting Church)**

The Uniting Church at Kingston (Rowallan Park) hosted a visit by the Community Affairs References Committee and Secretariat on Thursday 12 March 2015 prior to the Hobart public hearing. The purpose of the visit was to inspect the new accommodation constructed at this site for young people with severe disability. This accommodation has a range of different supported living options with a community feel.

The committee was presented with an overview of the project by Richard and Janine Romaszko, Lucia Fitzgerald and other members of the Kingston congregation. This project has been in planning for over nine years and was inspired by the needs of the Romaszko's daughter, Elise, who has Down syndrome. Elise would often ask her parents about the future:

*'...where will my friends and I live?'*

The congregation believes that this project is not simply about buildings, but rather creating a series of inter-related communities—the community within the house, the community within the site, and the interactions with the surrounding community of Kingston. The committee heard that these types of projects cannot only be about 'bums on beds', there must be a sense that these people are valued as members of the communities that they live in. The overarching principle of supported accommodation must be—'Would you want to live here?'—as this is the basis of what builds a community.

The planning, capital funding, construction and on-going operation of the facility was discussed. Rowallan Park adopts an innovative structure with the Uniting Church as property owner, developer and landlord renting these units to young people. Optia is the disability support provider that manages the support services provided to these young people. Each young person is funded through an ISP.



**Photo 4.1: Residents relaxing in their home playing videogames**

4.62 However, despite the success of the Rowallan Park project, there are a number of issues surrounding this facility that illustrate some wider problems. First, this facility has been operational since October 2014, yet still has vacancies despite identifying suitable young people willing to accept a placement. Reverend David Parker described the frustrations of the Uniting Church:

The person has been selected and we are now three months down the track, and we still do not have the approval from the NDIS process. There seems to be significant confusion and a lack of clarity around the objectives and how you might run a business model that can provide service to customers as opposed to being bureaucratic. I do not have the detail, but in principle it is quite a significant issue right at the moment.<sup>75</sup>

4.63 The second issue is the source of funding for the Rowallan Park facility. Mrs Lucia Fitzgerald of the Uniting Church of Australia discussed the funding source for the current development at Rowallan Park and then highlighted impediments to future projects:

It was federal government money, and that gave certainty around the whole project because the money was there for the accommodation. It therefore allowed the state government to be aware of it, and they certainly came through with the individual support packages as required. The issue now with my portfolio is that we have available land to replicate the pilot project, but we do not have the capital for the accommodation, because that structure has now moved on; it is gone. We are now talking about what structure is going to assist us to replicate this model. At the moment, if we attach the capital with any type of individual person, there are problems. That is because all of a sudden you have to herd people together and for a reasonable amount of time, because a project, as Lindy said, takes a fair bit of time in planning and to coordinate before you actually get the accommodation on the ground. There, you see, is the problem.<sup>76</sup>

4.64 The committee notes that the funding for this project was provided through the discontinued Supported Accommodation Innovation Fund (SAIF) funded by the Commonwealth Government. This fund delivered one round of funding in early 2012 and was not continued.<sup>77</sup> This project:

[C]ommitted \$60 million for 150 supported accommodation places for people with disability. Projects included renovations to existing homes, pooled resources to build contemporary accommodation services close to

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75 Reverend David Parker, Chairperson, UnitingCare Tasmania, Hobart, 12 March 2015, p. 14.

76 Mrs Lucia Fitzgerald, Manager—Development Projects, Uniting Church in Australia, Synod of Victoria/Tasmania, *Committee Hansard*, Hobart, 12 March 2015, pp 5–6. See also: Mrs Delia Gray, Executive Manager, Community Services, Royal Rehab, *Committee Hansard*, Sydney, 19 February 2015, p. 37.

77 Department of Social Services, *Supported Accommodation Innovation Fund (SAIF)*, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-service-providers/supported-accommodation-innovation-fund-saif> (accessed 19 June 2015).

community and health services, or the modification of established buildings. Funding for this initiative ended in June 2014.<sup>78</sup>

*Block and individualised funding*

4.65 Funding for disability support services in Australia has traditionally been delivered as 'block funding'. Block funding is 'where a government or contracted service provider is funded to provide a defined disability support to a defined number of people or as many people as they can'.<sup>79</sup> In its submission, the Summer Foundation said:

The NDIS is a massive and complex reform. Unlike the existing disability service system in Australia that is largely a welfare-based and rationed model where people with disability are passive recipients of block-funded services, the NDIS is a market driven system based on rights where people with disability are empowered to make choices regarding services and supports.

The NDIS aims to provide individualised person-centred processes where people with disability have choice and control over the supports and services they need to make progress towards goals. People with disability will also have choice regarding who provides their supports and how they are delivered, the extent to which they manage their own funding and the level of risk they take in organising their lives.<sup>80</sup>

4.66 The committee received evidence from many witnesses indicating that the move to individualised funding would result in better outcomes. Mr Colin Rose noted that:

I live in shared accommodation. We get block funding, but it would be so much better if we had individualised funding. To keep me at the place I am in now is about \$120,000. If I had individualised funding, I could be out in the community for about \$60,000, so it just does not gel for me.<sup>81</sup>

4.67 Mr Glenn Foard, CEO of Melba Support Services agreed:

It might strike senators as a little strange, representing a service provider organisation as we do, but we do not want the funding coming to us as an organisation. We want the funding going to individuals. Our experience has been that when that happens—and it has happened in certain situations; we still have a lot of block funding arrangements in place, but where individuals have control over the support funding that is being provided to them—innovation follows, and great arrangements are put in place that

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78 Department of Social Services, *Submission 55*, p. 13.

79 Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, *Occasional Paper no. 39, Effectiveness of individual funding approaches for disability support*, 2010, [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/op29.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/op29.pdf) (accessed 9 June 2015).

80 Summer Foundation, *Submission 109*, p. 64.

81 Mr Colin Rose, Board Member, Melba Support Services, *Committee Hansard*, Melbourne, 11 March 2015, p. 6.

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allow people to exercise genuine choice and that allow people to live in a home they genuinely can call their own. That is one of the important things that I think we need to continue to progress.<sup>82</sup>

4.68 The committee also received evidence that outlines the benefits of young people being able to choose their own supports such as rehabilitation services or support for activities in the community. However, concerns were expressed to the committee about the funding pathway for capital investment in specialised disability accommodation.

I would like to just comment on the individualised funding versus the block funding. Individualised funding meets lots of needs; it gives respect, autonomy—there are many, many pluses. I would suggest that the experience of our members is that there is also a need for block funding. One member established group housing for young people with ABI, and that could only have been done with block funding. If there are a dozen people who each had an individualised package, the work involved in getting those dozen young people in the room to put the capital upfront to build the facility needed for the care would have meant it would not have happened. With respite care, for example, the individualised package is good—there are huge advantages—but someone has to actually bankroll the facility. So the mix of block funding and individualised funding has got to come together. We come across it time and time again.<sup>83</sup>

4.69 The committee recognises the importance of individualised care packages for young people with disability as part of the NDIS's movement to person-centred care. However, the committee also notes the difficulties that arise with respect to funding capital works. State and Commonwealth Governments should give consideration to capital funding for construction of specialised disability accommodation.

#### *Alternative approaches*

4.70 Ms Lindy O'Neill of UnitingCare Tasmania noted that disability housing needs to heed some of the lessons from the aged care sector.

It could be some sort of bucket—for want of a more appropriate professional term—there at the start so that people can build. Then, if clients do come with money, their money goes back in the bucket and then, when they move on, it comes back out. But someone has to fund the bit at the start, because it is fraught with danger. What happens if a person wants to move out and take their money with them? What happens to the rest of the people who are still there? If you end up with a situation like we have at Rowallan Park, where we have vacancies, and no-one can go in, how does that work?...

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82 Mr Glenn Foard, CEO, Melba Support Services, *Committee Hansard*, Melbourne, 11 March 2015, pp 5–6.

83 Mr Denis Fitzgerald, Executive Director, Catholic Social Services Victoria, *Committee Hansard*, Melbourne, 11 March 2015, p. 6.

It is similar to what happens in aged care where you pay to go in and then you can take your money out when you go, but someone has to underwrite it at the beginning because it cannot start from fresh air. These buildings cost a lot of money.<sup>84</sup>

4.71 In evidence to the committee, Professor Way of Alfred Health described the approach taken by accident compensation schemes such as the Transport Accident Commission and the Workcover Authority:

What we see is a quite different response, because they have a different financial interest. So their response has been around whole-life-cycle costs for the individual, with the individual making the choices. They will create packages of care, opportunity for residences and so on—all the things that we have been talking about—because it is in their financial interest to do so.<sup>85</sup>

The issue of statutory personal injury schemes will be discussed further in the next chapter.

4.72 The committee also received evidence on a range of other schemes that may help bridge the capital funding gap for 'bricks and mortar' including allowing not-for-profits and government—owners of housing stock—access to equity in this existing stock to finance new development. Mr Gordon Trewern of Nulsen Disability Services stated:

Nulsen, for example, has nearly 30 government provided group homes. Those assets sit on the state register. If those assets sat on our balance sheet we would be able to use those as leverage for investments to actually build additional innovative options for people. So I think we need to look a little more laterally at how we use some of these assets. Currently, I would call those 'dead' assets that are not really working to the benefit of building housing capacity, whether that be group homes, individual options or apartments or whatever it might be.<sup>86</sup>

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84 Ms Lindy O'Neill, CEO, UnitingCare Tasmania, *Committee Hansard*, Hobart, 12 March 2015, p. 5.

85 Associate Professor Andrew Way, Chief Executive Officer, Alfred Health, *Committee Hansard*, 11 March 2015, p. 7.

86 Mr Gordon Trewern, CEO, Nulsen Disability Services, *Committee Hansard*, Perth, 17 February 2015, p. 43.

See also: Mrs Yvonne Kromkamp, CEO, Mt St Vincent Nursing Home and Therapy Centre Inc., *Committee Hansard*, Hobart, 12 March 2015, p. 6. The nursing home has funded a separate wing of the nursing home dedicated to young people with appropriate supports and activities. This has been funded through a mortgage facility extended on the nursing home.

Mr Christos Iliopoulos, CEO, Freedom Housing, *Committee Hansard*, Melbourne, 11 March 2015, p. 56. Mr Iliopoulos cites the defence Housing model as an example of funding. Defence housing finances the building, but then sells to investors who keep the property for nine years' with a guaranteed tenant.

4.73 Dr Bronwyn Morkham raised the concept of delinking housing from the disability sector to allow the department responsible for public housing to focus on what it does best—deliver housing:

The YPIRAC program has demonstrated absolutely clearly why disability services should not be delivering housing anymore. Most recently, we have had one of the final YPIRAC group home developments delivered in New South Wales—nine years, it took. We do not have nine years to wait. This is not their expertise and it should not be left there anymore, so we want to see disability service providers completely de-linked from housing development and delivery. It should not sit with them at all.<sup>87</sup>

#### *Committee view*

4.74 It is the committee's view that there is an inadequate supply of specialist disability accommodation (SDA). The committee notes the success of previous Commonwealth programs such as SAIF in increasing this supply. This will be discussed in later chapters. At the state level, there needs to be a co-ordinated approach to ensure that young people living in or at risk of entering residential care have priority on public housing lists. Further, when young people leave existing housing to temporarily enter the health or aged care system that those public housing places are protected.

4.75 The committee notes that there is not a 'one size fits all' with regard to SDA and that the states, Commonwealth and the not-for-profit sector need to work together to ensure that a range of SDA options are available. Finally, future and existing housing projects need to consider how they interact with the community and support services to ensure that they are sustainable. The next chapter will explore the housing issue and the NDIS further.

### **Regional, rural and remote communities**

4.76 The committee has received evidence indicating a range of additional constraints for those young people living with disability in rural and regional Australia including Aboriginal and Torres Strait Islander peoples. Many young people living in non-metropolitan Australia have poor access to services locally due to geographic isolation and low population density. This problem is compounded further by poor access to suitable transport options to access centralised services and often leads to a young person being placed in a RACF rather than receiving additional supports in the community.<sup>88</sup>

4.77 Independent Advocacy Townsville described the experience of one its clients who was transferred from a hospital to a RACF an hour and half from their hometown where she now has 'no supports, family or friends'.<sup>89</sup> In her submission, Ms Jane

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87 Dr Bronwyn Morkham, National Director—Young People in Nursing Homes National Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 15.

88 Ms June Reimer, Deputy Director, First Peoples Disability Network, *Committee Hansard*, Sydney, 19 February 2015, p. 3.

89 Independent Advocacy Townsville, *Submission 1*, p. [1].

Thomas explained the difficulty her brother has finding a place to live in their rural Victorian community.<sup>90</sup>

4.78 The lack of accommodation and support services is compounded by higher rates of disability amongst those living in rural, regional and remote areas as opposed to those living in major metropolitan areas. In its submission, the National Rural Health Alliance (NRHA) noted that:

- the proportion of people living with a disability is higher in Inner Regional, Outer Regional and Remote areas than in Major Cities; 22%, 20% and 17% respectively.
- the burden of chronic conditions (the leading cause of disability in Australia) increases with remoteness, particularly among Aboriginal and Torres Strait Islander peoples.<sup>91</sup>

### ***Aboriginal and Torres Strait Islander peoples***

4.79 Many Aboriginal and Torres Strait Islander peoples live in regional, rural or remote areas.<sup>92</sup> The NRHA states that the prevalence of disability amongst Aboriginal and Torres Strait Islander people is higher than in the overall Australian population citing the following statistics:

- the overall rate of disability among Aboriginal and Torres Strait Islander peoples was 21.1%;
- after adjusting for differences in the age structure of the two populations [ATSI and non-ATSI], Aboriginal and Torres Strait Islander peoples were 1.7 times as likely as non-Indigenous people to be living with disability;
- rates of disability peaked at an earlier age for Aboriginal and Torres Strait Islander peoples than for non-Indigenous people, reflecting the earlier onset of chronic conditions, such as heart disease and diabetes;
- Aboriginal and Torres Strait Islander children aged 0-14 years had much higher rates of disability than non-Indigenous children (14.2% compared with 6.6%);
- Aboriginal and Torres Strait Islander adults in the age range of 25-54 years had rates of disability that were between 2.0 and 2.5 times the corresponding rates for non-Indigenous adults; and
- in the 35–44 years age group, the differences in disability rates for Aboriginal and Torres Strait Islander people and non-Indigenous people were significantly different for both men (35.1% compared with 12.3%) and women (29.0% compared with 12.5%).<sup>93</sup>

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90 Ms Jane Thomas, *Submission 85*, p. [1].

91 National Rural Health Alliance, *Submission 136*, p. [2].

92 National Rural Health Alliance, *Submission 136*, p. [2].

93 National Rural Health Alliance, *Submission 136*, p. [2].

4.80 The committee received evidence during its Darwin hearing highlighting two disabilities that disproportionately affect Aboriginal and Torres Strait Islander peoples—Foetal Alcohol Spectrum Disorder (FASD) and Machado Joseph Disease (MJD). Mr Trevor Sanders of the Anyinginyi Health Aboriginal Corporation (AHAC) highlighted that not only do people in remote areas struggle to access services, they struggle to even have their disability identified. The committee heard that there is no word for disability in Aboriginal and Torres Strait Islander languages.<sup>94</sup> Although this reflects an inclusive culture where everyone is valued as a member of the broader community, it also poses problems as those people with disability are less likely to ask for and receive the support they need. Mr Sanders noted the scale of unidentified disability and possible unmet need:

As I said, government figures said there are about 22 people in the Barkly that are FASD affected. We think it is closer to 600.<sup>95</sup>

4.81 Mr Sanders told the committee that those with FASD will be included in the NDIS trial site and outlined some of the issues that had delayed the rollout of services:

Because it has not been on the radar, when we got into this trial we said, 'We know it's out there'...

So our thing was, 'You know it's there; help us build a service. Give us the money and build a service.' The problem we struck is that it has been like a sleeping monster and the government has not agreed on a diagnostic tool. So clinicians have not been able to sit down and go through a process to say, 'This child or this adult has FASD.'<sup>96</sup>

4.82 Despite this, AHAC has proactively put in place a service that seeks to provide supports for those with FASD:

We are using the NDIS as a catalyst to set up services. We have taken what we call the 'field of dreams' approach. If ever you saw the movie with Kevin Costner—not my favourite actor—the message was: build it and they will come. Just do it. That is exactly the approach we have taken. We have set up a clinical framework with Professor Elliott, the paediatrician from Westmead, working closely with the paediatricians at Alice Springs. They have told us what they want in terms of school reports and the history of the mum with alcohol. They need a speechy, occupational therapist, exercise physiologist and a psychologist, so we have engaged them—without government funding, yet, but we have just put them in place. The only way we will find out the level of the problem is by getting the services up, seeing what is out there and engaging with the community—which

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94 Mr Trevor Sanders, General Manager, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Darwin, 1 April 2015, p. 27.

95 Mr Trevor Sanders, General Manager, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Darwin, 1 April 2015, p. 23.

96 Mr Trevor Sanders, General Manager, Anyinginyi Health Aboriginal Corporation., *Committee Hansard*, Darwin, 1 April 2015, p. 19.

Aboriginal organisations have got an advantage in doing—working closely with schools and communities.<sup>97</sup>

The committee notes the scale of FASD in the Tennant Creek community and other remote communities throughout northern Australia. It is important that the NDIS work closely with community health services such as AHAC to provide diagnostic and early intervention services, and other supports to those with FASD.

4.83 Ms Massey Bodill of the MJD Foundation noted the complete absence of appropriate care facilities in remote communities:

When they require assistance from outside the family, as increasingly they do, there is very little appropriate care available to people who have MJD and who live in remote NT communities. There is not one functioning 24-hour residential-care facility in any of the 16 communities we are working in. There is in fact very little more than a daily meal service in most of those communities.

Ms Bodill emphasised that many young people requiring high level care and support are forced to leave their local communities and move to a regional centre, often many hundreds or thousands of kilometres from their home:

Currently our clients are forced to move into appropriate care facilities in towns—in Darwin, Katherine and Alice Springs—when their family care breaks down. Some have moved into aged-care facilities, some into facilities for younger people with disabilities. None of them have been able to stay close to their homes and families; none of them are cared for in language or are able to receive regular family visits; none of them have been able to maintain that most significant connection to country.<sup>98</sup>

4.84 Advocacy and assisted decision-making is critical to ensure that Aboriginal and Torres Strait islander peoples are aware of the services available and how to access them. Ms June Reimer of the First Peoples Disability Network stated:

The issue is that the way the current state funding rounds are going individual advocacy organisations will be defunded, because they see the NDIS or NDIA being the avenue for individuals to have their self-styled advocacy, which will not work, particularly with Aboriginal communities when they do not know how to deal with bureaucracy. They need individual advocacy even they do not understand what advocacy means sometimes and they just know they need somebody to support them. They do not use terminology like 'advocacy' or 'case managers'; they just need somebody in the community to support them to navigate the system. Sitting alongside the NDIA, we see the need for Aboriginal workers who can support people—

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97 Mr Trevor Sanders, General Manager, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Darwin, 1 April 2015, p. 20.

98 Ms Elizabeth Massey Bodill, Director, Research and Community Services, *Committee Hansard*, Darwin, 1 April 2015, p. 21. See also: BaptistCare, *Submission 130*, p. 1. Even when a RACF is available, often the additional support services are not available. This submission states that 'It is [our] experience that there is virtually no support available for young people in residential aged care in rural and regional communities'.

with whatever title you want to give them—because the other issue right across the board is the low take-up rates by Aboriginal people with the NDIA. So you are not going to solve this for those living in nursing homes or hospital settings when they do not even know about it because, generally, when we talk to Aboriginal communities, the length and breadth of Australia, people have never heard of the NDIA or NDIS.<sup>99</sup>

4.85 The committee recognises the difficulty in providing a range of support services and accommodation options in regional areas where population density is low and where those accessing the services may be spread over a large geographic area. The committee also recognises that in some cases a RACF may be the only option available to assist a young person to remain in their local community. The committee received evidence suggesting that demand for high level care and accommodation will continue to grow in these remote communities.<sup>100</sup>

#### *Committee view*

4.86 It is important for people living in regional, rural or remote locations to be able to access a range of options and to be able to make decisions about their support. The committee notes that a larger proportion of those living in rural locations 'are cared for by family or friends'.<sup>101</sup> On the one hand, this can reflect a lack of other options, but can also reflect the choice of a young person, especially Aboriginal and Torres Strait Islander peoples wanting to remain 'on-country'. It is the committee view that all young people no matter where they live are provided choices and supported where they wish to live.

4.87 The committee notes the scale of FASD in the Tennant Creek community and other remote communities throughout northern Australia. It is the committee view that the NDIS should consider how its supports those with FASD and should also work closely with community health services such as AHAC to provide diagnostic and early intervention services, and other supports to those with FASD.

### **Assisted decision making and advocacy**

4.88 In previous sections of this chapter, two key themes have been identified and discussed— first, a siloed service delivery system that is difficult to navigate and second, delivering services using a person-centred approach. The committee has received evidence describing the apparent disconnect between these two ideas. Many submissions have noted that young people living in or at risk of living in RACF are often vulnerable people who are voiceless, and are hence unable to participate in the decision making process surrounding their care. Mr Rick van de Paverd was recently a full-time carer for his wife until his own diagnosis with a terminal condition, is concerned for his wife when he dies:

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99 Ms June Reimer, Deputy Director, First Peoples Disability Network, *Committee Hansard*, Sydney, 19 February 2015, p. 5.

100 See, for example: Ms Massey Bodill and Mr Trevor Sanders, *Committee Hansard*, Darwin, 1 April 2015, pp 21–23.

101 National Rural Health Alliance, *Submission 136*, p. [2].

If I am out of Anna's life there will be very little advocacy on her behalf, which is a desperate concern for us both. Anna will have no Case Manager, no appointed agent, no ally to assist with any potential problems she lives with, other than her family.<sup>102</sup>

4.89 The committee has also received evidence about inappropriate decision-making which suggests that RACF 'staff will often make decisions for residents thereby removing their autonomy to live their own life'. This often reflects staff that do not have the relevant skills or experience to identify the needs of people with 'complex communication' needs.<sup>103</sup>

4.90 Poor or non-existent advocacy can result in unintended consequences. Ms Sally Korbelt describes her son Paul's experience when attempting to find new accommodation:

The Disability Support Register [Victorian DHHS] had never met Paul and had never seen the home [they] were suggesting which was totally unsuitable. Paul would not have been able to manoeuvre his wheelchair in the limited space available and the conditions were appalling...

As I refused this offer, I felt it then worked against us. Several people I have asked to assist with Paul's plight have endorsed this.<sup>104</sup>

4.91 Mrs Sonia Di Mezza noted the importance of advocacy stating:

Advocacy is completely crucial. I always say that, once you are in a nursing home, getting that person out is a very, very difficult thing to do.<sup>105</sup>

4.92 Life Without Barriers (LWB) is an organisation that supports a person-centred approach by involving the young person in the decisions that will affect how they lead their lives. In its submission, LWB stated that:

the people we support play the biggest role in designing their supports and choosing the services that they need.<sup>106</sup>

### ***The 'systems wrangler'***

4.93 Many submissions and witnesses have highlighted the importance of a young person having a strong advocate or case manager:

Where we see success, always there is strong advocacy, case management and...

A strong family member who will not give up; who knows and who is able to actually go out there and find the information. Other family members who do not have the time, who are working and who have other burdens on

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102 Hendricus (Rick) van de Paverd, *Submission 88*, p. 4.

103 Queensland Aged and Disability Advocate, *Submission 92*, p. 2.

104 Ms Sally Korbelt, *Submission 99*, p. [1].

105 Mrs Sonia Di Mezza, Deputy CEO, ADACAS, *Committee Hansard*, Canberra, 15 May 2015, p. 26.

106 Life Without Barriers, *Submission 148*, p. 2.

their time, cannot always get access to that information. So it very much about knowing what you know, and then being able to find that information so you can find your way through the system. Disability is complex and aged care is complex. Trying to bring the two together just makes it very, very difficult.<sup>107</sup>

4.94 Throughout its public hearings many witnesses have raised the need for a 'systems wrangler', a key person or an organisation who can help parents, families and individuals to understand and navigate the different departments and programs currently available. Dr Bronwyn Morkham of the Young People in Nursing Homes National Alliance (YPINHNA) defines system wranglers as:

[P]eople who are very skilled, who know about the different ways those health, housing, disability, and education sectors work, and can go in and work with people in those sectors to extract the services and supports each individually provides, but to deliver them in an integrated way for the person.<sup>108</sup>

4.95 Mr Alan Blackwood of YPINHNA identified why case management is currently not working:

The trouble we have had with case management over the years—which is probably the latest profession to have come into this care sector—is that generally it only works in the program that funds it. If you are a home community care case manager, that is all you do. If you are a disability case manager, you are only mandated to work with that bit of funding you have in that one program. So if the person you are working with has needs in health or education, you actually have no mandate to go and sort that.<sup>109</sup>

Mr Blackwood also noted that in order for case management to work, case managers must be 'given a mandate to work across sectors'.<sup>110</sup>

4.96 An example of a program that successfully utilises a 'system wrangler' is the National Younger Onset Dementia Key Worker Program (YODKWP). The key worker 'acts as a primary point of contact for people with YOD, their families and carers' providing 'information, support, counselling and help with effectively engag[ing] with services appropriate to their individual needs'.<sup>111</sup> In its submission,

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107 Mrs Natasha Chadwick, Managing Director, Synovum Care Group, appearing on behalf of Leading Age Services Australia, *Committee Hansard*, Sydney, 19 February 2015, p. 20.

108 Dr Bronwyn Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 16.

109 Mr Alan Blackwood, Policy Director, YPINH, *Committee Hansard*, Melbourne, 11 March 2015, p. 24.

110 Mr Alan Blackwood, Policy Director, YPINH, *Committee Hansard*, Melbourne, 11 March 2015, p. 24.

111 Alzheimer's Australia, *National Younger Onset Dementia Key Worker Program*, <https://fightdementia.org.au/support-and-services/services-and-programs-we-provide/national-younger-onset-dementia-key-worker-program> (accessed 19 May 2015).

Alzheimer's Australia related the story of a young Victorian man who worked with a key worker:

A key worker in Victoria supported a person and his family to accept a recent diagnosis of Fronto-Temporal Dementia. The man was supported by the YODKW to disclose his diagnosis to his employer and receive entitlements when he decided he was no longer able to work. The key worker worked with the football club of which the client was a long standing member to support his ongoing involvement in the club.

The key worker also provided support to the client's teenage children, including working with the school to ensure supports were put in place. This has been done while linking the family into a number of other services and assisting with complex behavioural and psychological symptoms that needed extra support. This client's wife has commented that she does not know that she would have coped had it not been for the support from the YODKWP.<sup>112</sup>

4.97 The role of a 'systems wrangler' will be discussed further in Chapter 5.

### ***Advocacy and complaints resolution***

4.98 The previous section has discussed the importance of a 'system wrangler' who can assist young people to negotiate the service delivery system and obtain the best outcome for them when planning their future. Equally, the other important role that advocacy should fulfil is to advocate for young people experiencing systemic or persistent problems where they live or with the services they receive.

4.99 There are young people who have a range of fundamental needs that are not being met and no one to advocate on their behalf:

For him it is not about the NDIS; it is about: 'Will I get a shower?' 'Will someone come and help me in and out of bed?' Those are the issues he is thinking about. He does not care what it is called. He did not understand any of that, and the service providers were all assuming somebody else was doing it, so his application is only now going in with our support.<sup>113</sup>

4.100 Ms Mary Mallett of Disability Advocacy Network Australia spoke about the role that an advocate can play in solving issues that are quite fundamental to the privacy of young people living in the aged care facilities. For example:

At one of the regional places I am thinking about, nobody is allowed to have a lock on the door; it is all about safety. So the advocate who goes in and tries to help the people in that facility spends a long time over months and months trying to support people to, for instance, get doors that they can lock themselves so that people with dementia cannot come in all the time rifling through their drawers breaching the privacy of everybody in the place.<sup>114</sup>

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112 Alzheimer's Australia, *Submission 57*, p. 6.

113 Mrs Fiona May, ADACAS, *Committee Hansard*, Canberra, 15 May 2015, p. 27.

114 Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 15 May 2015, p. 25.

4.101 Ms Helen Bedford of Families Australia noted:

We know that there are often visitor programs or advocacy groups that go in for older people in nursing homes, but the feeling was that there needed to be a specially targeted program when younger people were in nursing homes or residential care.<sup>115</sup>

4.102 The committee recognises that there are a number of statutory positions to which young people can complain to. However, there are inconsistencies between jurisdictions with regard to what types of organisations an individual may lodge complaints about. For instance, if a young person had a complaint about an aged care facility, they could not complain to the WA or Victorian Ombudsman as these bodies 'cannot deal with private individuals or businesses'.<sup>116</sup> However, the NSW Ombudsman may investigate 'organisations delivering community services'—including RACF—and also administers an 'Official Community Visitor' scheme. The Official Community Visitor can 'help resolve issues of concern at the local level'. It is possible to request a visit from an 'Official Community Visitor'.<sup>117</sup>

4.103 The ACT has a dedicated advocacy scheme for young people living in aged care. In the ACT there are two 'Official Visitors' who are appointed by the Minister to 'undertake visits and complaints resolution functions for people with disability living in the community or, for those people aged under 65 years living in [RACF] in the ACT'. The Official Visitor Scheme has also developed a Self-Advocacy Tool Kit to raise awareness of the scheme.<sup>118</sup>

4.104 The success of the ACT Government's 'Official Visitor' program is noted and it is the committee's view that the Commonwealth should accept a lead role to ensure young people in all jurisdictions have access to an adequate complaint resolution process such as the ACT Government's 'Official Visitor' program or the NSW Government's 'Official Community Visitor' scheme.

### ***Funding***

4.105 The committee received evidence from the Department of Social Services saying that states/territories and the Commonwealth share responsibility for the provision of disability advocacy services. The Commonwealth directly distributes funding through the National Disability Advocacy Program (NADA) and the National Aged Care Advocacy Program (NACAP). Although the NACAP is nominally

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115 Ms Helen Bedford, Policy Officer, Families Australia, *Committee Hansard*, Canberra, 15 May 2015, p. 12.

116 Victorian Ombudsman, *What we can and cannot investigate*, <https://www.ombudsman.vic.gov.au/Complaints/What-We-Can-and-Cannot-Investigate> (accessed 15 June 2015). Ombudsman WA, *What you can complain about*, <http://www.ombudsman.wa.gov.au/Complaints/What.htm> (accessed 15 June 2015).

117 Ombudsman NSW, *What we do*, <http://www.ombo.nsw.gov.au/what-we-do/about-us/what-we-do> (accessed 15 June 2015).

118 ACT Government, *Submission 140*, p. 2.

available to all aged care residents (including young people), it is more often used for those aged over 65 years as they make up the majority of aged care residents.<sup>119</sup>

4.106 Ms Mary Mallet of the Disability Advocacy Network Australia noted that:

The NACAP is a very small program. There are only nine federal-funded services. There are two in the Northern Territory, but only one agency in each of the other states and territories...

Many of the activities that they do are about educating and providing information to workers and staff and people coming into those aged-care services, and not so much of the funding is available for individual advocacy. The quantum of advocacy available is very limited. The brochures and the information about those services are meant to be available in those residential facilities, but there is not likely to be brochures available about any of the other disability advocacy organisations. The staff are fairly unlikely to know about them or to refer people through...

Not only are there significant problems for some of these younger people, but they are even less likely to be able to get help with their problems than other people with disabilities living in other places.<sup>120</sup>

4.107 The committee received significant evidence relating to the inadequacy of funding for advocacy and assisted decision-making. Alzheimer's Australia (AA) noted that the key worker program is in jeopardy as this program's funding will be subsumed by the NDIS.<sup>121</sup> AA noted in further evidence to the committee that 'there is not a place in the NDIS to fund that advocacy role in the same way that the key workers have been able to support people'.<sup>122</sup>

4.108 Ms Lorraine Gibbs of the Darwin Community Legal Service noted the level of uncertainty around continuing funding for advocacy programs through the Commonwealth Department of Social Services:

Both of those programs under review. We understand that the disability advocacy program will be refunded, but we do not have that in writing and we do not know to what level of funding that will be. We anticipate—and hope, as with all of us here—that the aged advocacy program will continue, and the same with the NTG [Northern Territory Government]. Most of our

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119 Dr Nicholas Hartland, Branch Manager, Department of Social Services, *Committee Hansard*, Canberra, 15 May 2015, pp 52–54. See also Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 15 May 2015, pp 23–24.

120 Ms Mary Mallett, Chief Executive Officer, Disability Advocacy Network Australia, *Committee Hansard*, Canberra, 15 May 2015, p. 20.

121 Alzheimer's Australia, *Submission 57*, p. 7.

122 Dr Ellen Skladzien, National General Manager, Policy and Programs, Alzheimer's Australia, *Committee Hansard*, Sydney, 19 February 2015, p. 15.

funding is through the DSS and a small amount is from the NTG for disability advocacy.<sup>123</sup>

4.109 Ms Mary Mallett of Disability Advocacy Network Australia (DANA) noted that 'even though the advocates and advocacy organisations in the [NDIS] trial sites have an increased workload, there has been no recognition of that in the funding'.<sup>124</sup>

4.110 The NDIA has recognised the importance of assisted decision making in helping a young person choose an appropriate NDIS support package and to ensure it is appropriately delivered. Mr David Bowen, CEO of the NDIA spoke about the ability to fund 'Information, Linkages and Capacity Building' (ILC) as part of NDIS packages in the future:

We think it needs to be very much at the community level, very close to people, well integrated into other community supports so it is about helping people with the connection to the community as well as helping them through all of the different systems, including into the NDIS. It will become a significant resource that really does not exist as part of the trials.<sup>125</sup>

4.111 Although the committee is pleased to note the likely inclusion of ILC in NDIS packages, the committee is concerned about what happens to those not living in NDIS trial areas between now and the rollout of the full scheme.<sup>126</sup>

### ***Committee view***

4.112 This section considers two broad ideas—that young people need support with decision-making and with complaint resolution. It is clear to the committee that young people are currently not receiving adequate support in either of these areas and that largely this is a function of funding. The committee believes that if young people were assigned a key worker to assist with planning and decision making this would result in more informed placements. The YODKWP will be discussed further later in the report.

4.113 The committee also accepts that there is a level of inconsistency between different states with regard to complaint resolution. It is the committee's view that best practice schemes such as those found in the ACT and NSW should be observed and replicated in all states and territories with the Commonwealth playing a lead role in implementation.

### **Training the workforce**

4.114 In Chapter 3, the issue of aged care workers not being suitably experienced or trained to work with people with disability was discussed. This generally results in

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123 Ms Lorraine Gibbs, Team Leader and senior Advocate, Darwin Community Legal Service, *Committee Hansard*, Darwin, 1 April 2015, p. 8

124 Ms Mary Mallett, CEO, ADACAS, *Committee Hansard*, Canberra, 15 May 2015, p. 27.

125 Mr David Bowen, Chief Executive Officer, NDIA, *Committee Hansard*, Canberra, 15 May 2015, p. 51.

126 The full rollout of the NDIS is expected to take up to five years from now. Western Australia has not signed up to the NDIS at this stage.

poorer outcomes for young people in care and manifests in challenging behaviours and incorrect or delayed diagnosis of diseases and conditions such as dementia, in addition to poor job satisfaction for those aged care workers.

4.115 The committee received significant evidence suggesting that specialised training may be one option that would lead to better outcomes for young people who live in a RACF. Mr Joe Smith, Manager—Step-out Community Access Service noted that 'the carers there [in aged care] are really well-meaning people, but they do not have the disability training'.<sup>127</sup> Other submitters noted that 'staff members are trained in aged care, but only a minority are also trained in the field of disability'.<sup>128</sup>

4.116 In their submission, Occupational Therapists Australia discussed the importance of 'investing in upskilling and developing the professional carer workforce so that [RACF] staff are able to provide the care and support' that young people need. This investment in human resources would yield dividends in 'productivity and professional carer workforce outputs'.<sup>129</sup> The Brotherhood of St Lawrence submitted that 'institutions that train staff for disability and aged care be encouraged to develop courses that integrate both areas'.<sup>130</sup>

4.117 In addition to training that assists staff to better understand people with disability, it is also important for aged care staff to understand young people and their needs. In evidence to the committee, Dr Adrienne Withall, Senior Lecturer at the University of New South Wales noted that placing older people who are 'frail and unsteady' together with young people who are 'fit and agile' and who sometimes exhibit 'behavioural issues' can be difficult to manage in the RACF environment.<sup>131</sup>

4.118 Dr Morkham explained that aged care workers not only needed training, but also required support as a young person is transitioned from hospital to an RACF. Often this is funded only for a short period of up to one month, if at all.

But, because it is such a short time, the moment they leave or the minute there is an emergency, the ambulance is called and we are back to the hospital. Sometimes we find the providers will say it is just too hard and close the door. So there are pockets where this is being trialled, where people are trying very hard, with good results. But, again, there is no systemic support for that either.<sup>132</sup>

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127 Mr Joseph Smith, Manager—Step-out Community Access Service, *Committee Hansard*, Darwin, 1 April 2015, p. 26. See, for example: Mrs Keryn Hickey, *Submission 106*, p. [2].

128 Ms Jennifer Nolan, *Submission 66*, p. [2].

129 Occupational Therapists Australia, *Submission 146*, p. [2].

130 Brotherhood of St Lawrence, *Submission 59*, p. 5.

131 Dr Adrienne Withall, Senior Lecturer, University of New South Wales, *Committee Hansard*, Sydney, 19 February 2015, p. 42.

132 Dr Bronwyn Morkham, National Director—Young People in Nursing Homes National Alliance, *Committee Hansard*, Melbourne, 11 March 2015, p. 27.

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***Committee view***

4.119 Just as RACF are not funded or designed for young people, the staff employed by these facilities are also not formally trained or experienced in caring for people with disability. It is the committee's view that all aged care staff should be required to undertake a component of their formal training in caring for people with disability. Further, RACF that accept a young person in a placement should be given specific training or support as a young person is transitioned into a RACF to ensure that the staff are able to meet the young person's health, social and behavioural needs. It is the committee's view that the key worker role that will be discussed further in the next chapter will facilitate provision of that support.



## **Chapter 5**

# **The Younger People with Disability in Residential Aged Care Initiative, the National Disability Agreement and the National Disability Insurance Scheme**

### **Introduction**

5.1 This chapter discusses the following terms of reference:

- (h) The impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation.
- (j) state and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care Initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth's contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction.

### **Younger People with Disability in Residential Aged Care Initiative**

5.2 The Younger People with Disability in Residential Aged Care (YPIRAC) Initiative was a Council of Australian Governments (COAG) agreement between the states/territories and the Commonwealth that commenced on July 2006.<sup>1</sup> This initiative had three key objectives:

- 1) move younger people with disability currently in residential aged care into appropriate supported disability accommodation; where supported disability accommodation can be made available and only if the client chooses to move;
- 2) divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation; and
- 3) enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care, and if residential aged care remains the only available suitable supported accommodation option.

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1 The YPIRAC Initiative was one of many programs funded under the Commonwealth State Territory Disability Agreement (CSTDA). The CSTDA provided the national framework for the delivery, funding and development of specialist disability services for people with disabilities. The CSTDA has now been replaced with the National Disability Agreement which will be discussed further in this chapter.

5.3 Participation by young people in this program was voluntary and focused on those aged 50 years or younger.<sup>2</sup>

5.4 In 2012, the YPIRAC targets were assessed in the final report for the YPIRAC initiative:

Over the five years of YPIRAC to 2010–11, an estimated 1,432 people 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).

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.<sup>3</sup>

5.5 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.

5.6 However, the study 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.<sup>4</sup>

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2 Commonwealth Department of Social Services, *Younger People with Disability in Residential Aged Care Initiative*, 7 November 2014, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative> (accessed 8 May 2015). As discussed in Chapter 2, this has resulted in a significant decrease in the numbers of young people under the age of 50 living in RACF whereas those aged 50 to 64 years have increased.

3 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).

4 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.

5.7 In its submission to the committee, Young Care noted that 'it was unanimously agreed that the funding pool of \$244 million was not sufficient to achieve complete resolution of the problem'. Further:

While YPRIAC achieved a drop of 22% of new admissions for young people entering aged care, a significant number of people were unable to access their services because funding could not cover all residents. Also, of greater concern is that a decline in the number of younger people in aged care plateaued after 2011. The shortcomings of YPIRAC were acknowledged in its 2009 Mid Term Review:

'It was originally anticipated that by the conclusion of the 2008-09 financial year, between 188-241 people would have been relocated from RAC (PO1). At the December 2008 reporting period however, the total number of YPIRAC relocated was 70.'<sup>5</sup>

Figure 5.1 below highlights the relative success that some states had over others:

**Figure 5.1: Extract from the Mid-term YPIRAC scheme report**

New South Wales	Original forecast to relocate between 44-88 people by June 2009, had achieved 2 relocations by December 2008.
Victoria	Original forecast to relocate 71 people by June 2009, had achieved 19 relocations by December 2008.
Western Australia	Original forecast to relocate 12 people by June 2009, had achieved 3 relocations by December 2008.
South Australia	Original forecast to relocate 24 people by June 2009, had achieved 17 relocations by December 2008.
Queensland	Original forecast to relocate between 35-43 people by June 2009, had achieved 25 relocations by December 2008.

Source: Department of Social Services, *Mid-term Review, Younger People in Residential Aged Care (YPIRAC) Program*, [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/ypirac\\_mter\\_report.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/ypirac_mter_report.pdf) (accessed 19 June 2015).

5.8 In its submission, MS Queensland noted that YPIRAC was a 'first step—not a finished solution'. Young People in Nursing Homes National Alliance (YPINHNA) agreed noting that the initial focus of the program was on those aged under 50. YPINHNA said:

YPIRAC's funding was also insufficient to enable participation by those outside the 'initial target group'. While the under 50s group has reduced over the term of YPIRAC's operation, the continued growth of the over 50s cohort has merely underscored the need for YPIRAC's targeted approach and dedicated funding stream to continue and expand...

YPINHNA highlighted that '90 per cent of admissions were aged 50–64'. Further to this, 'most jurisdictions interpreted the program reference "initial priority for those

aged 50 years of age" as an absolute eligibility criteria' and excluded those young people aged over 50 years from the program.<sup>6</sup>

5.9 Despite the programs shortcomings, the positive outcomes for some participants led to the expectation that the program would continue to be funded after June 2011, but this did not eventuate.<sup>7</sup> Dr Bronwyn Morkham, of the YPINHNA explained that not only did the states and territories choose not to fund the YPIRAC program beyond 2011, there is concern that the Commonwealth's contribution may not have been used for that purpose:

The Commonwealth recommitted its \$122 million through the National Disability Agreement. However, there is absolutely no capacity to know where that money has gone within the states. There is no transparency. It is meant to be kept sequestered for young people in nursing homes, to keep those services going that were set up under YPIRAC. We have had instances where state programs have said, 'Sorry, we are going to bring it back into the general pool for disability funding.' They are not maintaining them. There is no capacity to know what has happened to that money.<sup>8</sup>

5.10 From 2011, the Commonwealth funding for YPIRAC has been provided as a National Disability Specific Purpose Payment (ND SPP). Under these arrangements, 'there is no agreed mechanism for intergovernmental tracking of any governments' specified funding for the YPIRAC cohort...since 2010–11'.<sup>9</sup>

5.11 Many submitters noted that the states and the Commonwealth should collaborate and 'work together to fund a new initiative' similar to YPIRAC.<sup>10</sup> The committee notes that there is currently no dedicated program to support young people living in or at risk of entering RACF despite the Commonwealth continuing to provide its share of the funding.

### **National Disability Agreement**

5.12 On 1 January 2009, the National Disability Agreement (NDA) replaced the Commonwealth State and Territory Disability Agreement. The YPIRAC program and its funding were transferred into the NDA.

5.13 The NDA is a current COAG agreement between the states/territories and the Commonwealth that commenced on 1 January 2009. In its submission, the Department of Social Services states:

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6 Young People in Nursing Homes National Alliance, *Submission 93c*, pp 8–9.

7 MS Queensland, *Submission 96*, p. 5. See also: Young People in Nursing Homes, *Submission 93c*, p. 8.

8 Dr Bronwyn Morkham, National Director, Young people Living in Nursing Homes National Alliance, *Committee Hansard*, Sydney, 19 February 2015, p. 39. This money was provided over the life of the agreement resulting in the Commonwealth providing approximately \$24.4 million per annum. This money continues to be provided to the states although it is not attached to a specific program.

9 Department of Social Services, *Submission 55*, p. 9.

10 MS Queensland, *Submission 96*, p. 7.

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The NDA is the framework for the provision of government support for people with disability. The NDA is not a funding agreement. However, it does explicitly confirm jurisdictional responsibilities in relation to provision of disability services.

The states and territories are responsible for the provision of specialist disability services except for disability employment services which the Commonwealth accepts responsibility for.<sup>11</sup>

5.14 The NDA articulates a series of outcomes which COAG will strive to achieve including that:

- people with disability achieve economic participation and social inclusion;
- people with disability enjoy choice, wellbeing and the opportunity to live as independently as possible; and
- family and carers are well supported.<sup>12</sup>

5.15 In order to support the delivery of these outcomes, state and commonwealth governments will contribute to the following outputs:

- services that provide skills and support to people with disability to enable them to live as independently as possible;
- services that assist people with disability to live in stable and sustainable living arrangements;
- income support for people with disability and their carers; and
- services that assist families and carers in their caring role.<sup>13</sup>

5.16 A key part of the National Disability Agreement is the National Disability Strategy (the strategy) for 2010–2020. The strategy sets out 'a ten year national plan for improving life for Australians with disability, their families and carers'.<sup>14</sup> In its 2012 report to COAG, the strategy outlines a series of reforms including the need to:

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11 Department of Social Services, *Submission 55*, p. 9.

12 Council of Australian Governments, *National Disability Agreement*, <http://www.federalfinancialrelations.gov.au/content/npa/disability/national-agreement.pdf> (accessed 31 March 2015).

13 Council of Australian Governments, *National Disability Agreement*, <http://www.federalfinancialrelations.gov.au/content/npa/disability/national-agreement.pdf> (accessed 31 March 2015).

14 Australian Government Department of Social Services, *2010–2020 National Disability Strategy: An initiative of the Council of Australian Governments*, p. 8, [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/national\\_disability\\_strategy\\_2010\\_2020.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf) (accessed 9 June 2015).

Maintain innovative and flexible support models for people with high and complex needs—this may include options for younger people in, or at risk of entry into, residential aged care...<sup>15</sup>

5.17 The NDA and the NDS provide a framework in which the Commonwealth and state and territory governments can work together to deliver better outcomes for young people living with disability. Although the YPIRAC program has not been the panacea it was envisioned to be, in the time it was implemented (2006–2011), the program reduced the number of admissions and resulted in better life outcomes for those young people involved. One of the reasons YPIRAC was not as successful as it could have been is the lack of specialist disability accommodation available for young people to transition into. This has been discussed in previous chapters and will be explored in the next section on the NDIS.

### **National Disability Insurance Scheme**

5.18 In 2010, the Productivity Commission conducted a review into long term disability care and support in Australia.<sup>16</sup> As a result of this review, COAG agreed to establish the National Disability Insurance Scheme (NDIS) as a means to 'ensure that people with permanent and significant disability...receive support based on their needs, and have control and choice over this support'.<sup>17</sup>

5.19 Throughout this inquiry the committee has received evidence on the impact the NDIS will have on young people living in or at risk of entering residential care. Dr Bronwyn Morkham noted that if the NDIS acts as a silo and does not actively collaborate with service providers and state government departments, then the scheme will fail:

Just as disability services programs failed to deliver the necessary reforms on their own, the NDIS, as another disability services funding program, risks the same failure if it cannot deliver the joined-up responses YPINH need. Solutions must come from the development of integrated pathways, and the NDIS must work collaboratively with mainstream programs like health to develop them. Some of these programs in health do not actually exist yet, so people refer to health and say that they must do what they

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15 Australian Government Department of Social Services, *2010–2020 National Disability Strategy: Report to the Council of Australian Governments 2012: Laying the Groundwork 2011–2014*, p. 106, [https://www.dss.gov.au/sites/default/files/documents/01\\_2013/nds\\_first\\_year\\_final\\_-\\_20\\_12\\_12\\_2.pdf](https://www.dss.gov.au/sites/default/files/documents/01_2013/nds_first_year_final_-_20_12_12_2.pdf) (accessed 9 June 2015).

16 Australian Government Productivity Commission, *Disability Care and Support, Productivity Commission Inquiry Report—Overview and Recommendations, No. 54, 31 July 2011*, <http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf> (accessed 10 June 2015).

17 Department of Social Services, *Submission 55*, p. 13.

should do, but they do not actually have some of the community based programs we are going to need to make this a reality.<sup>18</sup>

5.20 The next sections will discuss a range of issues related to the NDIS and young people living in aged care.

### ***Specialist disability accommodation***

5.21 After its April 2015 meeting, the Disability Reform Council (DRC) acknowledged that it is unclear the extent to which the NDIS will support specialist disability housing. The DRC noted that the full scheme NDIS 'includes capital costs for specialist accommodation' and that 'some of these funds will need to support existing specialist accommodation supply'. The DRC recognised that NDIS funds will be available to:

[S]upport people with disability requiring an integrated housing and support model to access housing and to enable the market to generate and leverage new and innovative specialist disability housing.<sup>19</sup>

5.22 According to the Department of Social Services, the National Disability Insurance Scheme (NDIS) was intended to assist with support services not accommodation for people with disability. In its submission, the department stated that the NDIS:

[W]ill fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians)'.<sup>20</sup>

The Department added that state governments through:

[P]ublic and community housing providers will continue to provide accommodation for people in need of housing assistance...including appropriate and accessible housing for people with disability...

NDIS will be responsible for home modifications for accessibility for individuals in private dwellings.<sup>20</sup>

5.23 Some submitters agreed with the department's position; the Salvation Army National Secretariat stated:

[T]he level of support offered by NDIS may not be sufficient to help meet the accommodation needs of young people with high and complex needs...

It is our understanding that people under 65 years of age living in residential aged care may be eligible to receive assistance from the NDIS. On closer view, most of this support is offered only if residential aged care

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18 Dr Bronwyn Morkham, National Director, Young People living in Nursing Homes National Alliance, *Committee Hansard*, Sydney, 19 February 2015, pp 28–29.

19 Media Release, Senator the Hon Mitch Fifield, *COAG Disability Reform Council Communique*, 24 April 2015, <http://mitchfifield.dss.gov.au/media-releases/coag-disability-reform-council-communicu> (accessed 1 June 2015).

20 Department of Social Services, *Submission 55*, p. 14.

does not provide this support and relates to equipment, allied health services, and access/transport to community activities...

The NDIS specifically states that it excludes assistance for daily living expenses and accommodation charges...<sup>21</sup>

Further, 'there are currently no real, full-time alternative accommodation options outside of aged care [except for YoungCare]...available for young people with serious...disabilities'.<sup>22</sup> Other submitters expressed concerns about how the 'bricks and mortar' will be funded.<sup>23</sup>

5.24 However, despite the NDIS seeming to exclude support for provision of accommodation, the department has noted that the NDIS will be responsible for the 'user costs of capital in some situations'. The user cost of capital is defined as being the 'costs required to build and maintain a house or the cost of renting a property'. Furthermore, the department notes:

[U]ser cost of capital can be calculated as a yearly or per person amount, such as the annual cost of borrowing funds to purchase a house or building, or to finance additional features for a home.<sup>24</sup>

5.25 To place this concept in a more readily understood context, the most recent Commonwealth government disability housing initiative, the discontinued Supported Accommodation Innovation Scheme (SAIF), provided supported accommodation places at an average capital cost of \$400 000. If the NDIS were able to provide a user cost of capital—or provide for interest payments on the capital—as part of an Individual Support Package (ISP), this user cost of capital would amount to \$20 000 per annum.<sup>25</sup> It is not clear to the committee the circumstances under which the NDIS would deem it to be appropriate to contribute to these types of payments.

5.26 National Disability Services highlighted another type of funding for specialised disability accommodation potentially available under the NDIS:

The NDIA has also identified that there will be a group of participants who need access to specialised housing which is not available in the private market, or is significantly more expensive as a result of participants' disability. To help provide this accommodation, the NDIA will have \$700

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21 The Salvation Army National Secretariat, *Submission 33*, p. 6.

22 The Salvation Army National Secretariat, *Submission 33*, p. 6.

23 Name withheld, *Submission 97*, p. [2]. See also: NSW HACC Development Officers Network, *Submission 89*, p. 4.

24 Department of Social Services, *Submission 55*, pp 15–16.

25 This works on the assumption of an interest rate of 5 per cent. See also: Department of Social Services, *Submission 55*, p. 13. The Commonwealth committed \$60 million to fund 150 supported accommodation places through this fund. 'Projects included renovations to existing homes, pooled resources to build contemporary accommodation services close to community and health services, or the modification of established buildings.'

million per annum (at full implementation) to assist in the provision of specialised accommodation.<sup>26</sup>

Again, it is not clear to the committee who would be eligible for this funding.

5.27 In its submission, MS Queensland noted the importance of the NDIS clarifying its position in relation to housing:

At this critical stage of development of the NDIS new and appropriate accommodation alternatives must be created, developed, invested and constructed as appropriate accommodation solutions for young people. Simultaneously development of policy initiatives at state and federal levels that promote a place where we would all wish to live in our community, connected near family and friends and employment to promote active participation in the community is required.<sup>27</sup>

5.28 In its latest communique, the DRC has asked officials to:

[W]ork with the NDIA to support the development and testing of innovative accommodation pilots in trial sites that will help to expand the supply of appropriate and sustainable integrated housing and support models for people with disability. This may include existing, contemporary and/or innovative supports.<sup>28</sup>

This is in addition to a 'long awaited' housing discussion paper that the department has still not released. The department has indicated to the committee that this housing paper and housing policy will be released in September 2015.<sup>29</sup>

#### *Committee view*

5.29 The committee notes that the role of the NDIS in provision of specialised disability housing is unclear. On the one hand, the NDIA and DSS state that the NDIS is not responsible for the provision of housing, yet other evidence outlined above suggests that under some circumstances it does have a role. In its latest communique, the DRC has indicated that it will seek to clarify this position with the states. The committee expresses its frustration and disappointment that the disability housing discussion paper will now not be released until September 2015.

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26 National Disability Services, *Submission 90*, p. [3]. See also: Dr Nick Hartland, Group Manager, Department of Social Services, *Proof Estimates Hansard*, 4 June 2015, p. 134. Dr Hartland acknowledged that the Productivity Commission recommended that a figure of approximately \$550 million be made available to the NDIS for specialised disability housing.

27 MS Queensland, *Submission 96*, p. 7.

28 Media Release, Senator the Hon Mitch Fifield, *COAG Disability Reform Council Communique*, 24 April 2015, <http://mitchfifield.dss.gov.au/media-releases/coag-disability-reform-council-communiqu> (accessed 1 June 2015).

29 See: *Committee Hansard*, Sydney, 19 February 2015, p 62; *Committee Hansard*, Melbourne, 11 March 2015, pp 12–13. See also: Answers to Questions on Notice No. 6, Department of Social Services, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents), (accessed 19 June 2015).

5.30 The committee notes that there are mechanisms described above—such as user cost of capital—that may be useful in providing specialised disability accommodation to young people living with disability.

### *Systems wranglers*

5.31 In Chapter 4, the issue of assisted decision-making and advocacy were discussed. Evidence to the committee has identified a role for a 'systems wrangler' or key worker who can assist a young person and their family to understand and navigate the different departments and programs currently available. The systems wrangler could also assist a young person with their decision-making.

5.32 The National Younger Onset Dementia Key Worker Program (YODKWP) is highlighted as a successful program that acts as a 'systems wrangler', albeit for a discrete group of people—those diagnosed with Alzheimer's disease. The Commonwealth Government currently funds this program until 30 June 2016, when it is expected to be 'subsumed under the NDIS'.<sup>30</sup>

5.33 The committee received evidence from Ms Natalie Butler, Project Manager for the Summer Foundation's NDIS Connections project. Initially this project was proactively started and funded by the Summer Foundation. Ms Butler notes:

As of the end of 2014, 12 months into my role, I personally have worked with 29 young people living in nursing homes. The majority of these people were not known to existing disability services and many do not have a family member or advocate who can help them on their behalf. Most, as I said, were not aware of their eligibility under the NDIS.<sup>31</sup>

5.34 Ms Butler shared a case study with the committee that highlights the critical role that advocacy can play for voiceless young people:

I would like to talk to you a little bit about the process of what it takes to connect a young person to the NDIS. I will share with you a case study of a person that I have called Jack. It takes dedicated time to link Jack to the NDIS. Jack is a 52-year-old man with epilepsy who has been living in a nursing home for over 10 years. Using the online NDIS Access Checker, nursing home staff were advised that Jack was ineligible for the NDIS based on the postcode that was entered. Being fully aware that his address was in the trial catchment area, I followed up directly with the NDIA to rectify this online technical glitch that was incorrectly registering Jack's postcode as making him ineligible for the NDIS. After this problem was resolved, I supported Jack and nursing home staff to complete all application information online and again in paper form. I also provided advice on ways to simplify the application process based on readily available information. And those types of information included things like ACAT assessments and not waiting for medical specialists to complete information. In fact, nursing home staff can complete that information.

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30 Alzheimers Australia, *Submission 57*, p. 2.

31 Mrs Natalie Butler, NDIS Connections Officer, Summer Foundation, *Committee Hansard*, Sydney, 19 February 2015, p. 51.

Jack was subsequently deemed eligible for the NDIS and needed to complete a pre-planning activity prior to his meeting with the NDIA. As nursing home staff were at capacity with their workload, I worked with Jack over several meetings to help develop a rapport and build his capacity to describe his goals and aspirations. Jack, like all other participants, had his first face-to-face meeting with the NDIA at the planning meeting. Jack was well prepared for his first planning meeting and had a great outcome. Jack's story is an example of how people can very easily fall through the gaps. If it were not for my advocacy role in Jack's situation, he would have missed out on the opportunity of the NDIS.<sup>32</sup>

5.35 The NDIA has recently recognised the critical role of advocacy to this particular cohort and has agreed to fund the NDIS Connections project in the NDIS trial sites.<sup>33</sup>

5.36 The NDIA has recently released a discussion paper on Information, Linkages and Capacity Building (ILC). The NDIA recognises that:

[P]eople with disability engage both directly and indirectly with a range of informal and formal supports and resources over their lifetime, to assist them with their everyday needs and their social and economic participation.

The ILC:

[E]nables the NDIS to fund supports not directly tied to an individual and, by doing so, gives the scheme the ability to deliver its operational and strategic objectives.<sup>34</sup>

5.37 One of the ways that ILC could be provided is through a local area coordinator (LAC). An LAC will:

Ensure that people with disability, their families and carers, are able to make full use of the mainstream and other services (including diagnostic-specific information) available to them...and assist them to navigate the variety of NDIS supports.<sup>35</sup>

There has been no formal response to this discussion paper at the time of tabling.

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32 Mrs Natalie Butler, NDIS Connections Officer, Summer Foundation, *Committee Hansard*, Sydney, 19 February 2015, p. 51.

33 Answer to Question on Notice, National Disability Insurance Agency, 4 June 2015, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents) (accessed 9 June 2015).

34 National Disability Insurance Scheme, *A Framework for Information, Linkages and Capacity Building*, p. 1, [http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework\\_0.pdf](http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework_0.pdf) (accessed 10 June 2015).

35 National Disability Insurance Scheme, *A Framework for Information, Linkages and Capacity Building*, p. 8, [http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework\\_0.pdf](http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework_0.pdf) (accessed 10 June 2015).

### *Committee View*

5.38 Elements of the YODKWP and the Summer Foundation project address fundamental concerns of young people living with disability. First, the key worker program acts as a systems wrangler connecting young people to the supports they need. Second, the Summer Foundation project reaches out to young people currently living in aged care to assist them with options for re-engaging with the community and exploring the idea of transition. It is the committee's view that the key worker program (YODKWP) should be expanded to include all young people living in or at risk of living in aged care. The committee notes that the Commonwealth's contribution to the now defunct YPIRAC program—approximately \$25 million per annum—could be used to fund this program.

### *National Injury Insurance Scheme*

5.39 Currently, there are a range of statutory personal injury schemes in Australia. These schemes provide compensation in the event of a catastrophic injury as the result of motor vehicle or workplace accidents. As these are mostly state based schemes, they vary in many ways including whether or not they are 'fault based' and the extent of coverage—provision for income replacement, treatment, rehabilitation, compensation for permanent impairment.<sup>36</sup>

5.40 When the Productivity Commission (PC) was conducting its review into the disability care and support, it made two key recommendations. One was for the formation of a NDIS, which is discussed above. Second, was for the formation of a National Injury Insurance Scheme (NIIS):

[T]o address catastrophic injuries from accidents, such as quadriplegia, acquired brain injuries, severe burns and multiple amputations. The scheme would comprise a coherent set of state-based, no-fault arrangements for providing lifetime care and support, building on existing schemes. It would have the same basic goals as the NDIS, but would be funded differently.<sup>37</sup>

5.41 The review also noted that standardisation of statutory personal injury schemes across the nation will provide better outcomes for individuals:

A no-fault National Injury Insurance Scheme, comprising a federation of individual state and territory schemes, would provide fully-funded care and support for all cases of catastrophic injury. It would draw on the best schemes currently operating around Australia. State and territory governments would be the major driver...<sup>38</sup>

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36 Suncorp, *Submission 100*.

37 Australian Government Productivity Commission, *Disability Care and Support, Productivity Commission Inquiry Report—Overview and Recommendations, No. 54, 31 July 2011*, p. 10, <http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf> (accessed 10 June 2015).

38 Australian Government Productivity Commission, *Disability Care and Support, Productivity Commission Inquiry Report—Overview and Recommendations, No. 54, 31 July 2011*, p. 3, <http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf> (accessed 10 June 2015).

5.42 Standardisation to a 'no-fault' scheme is also an important element of personal injury schemes. The Treasury, in its Consultation Regulation Impact Statement noted the critical difference between a no-fault and fault based scheme:

[S]ome motor vehicle accident insurance schemes are fault-based, meaning that individuals who cannot prove the fault of another party can be ineligible for care and support.<sup>39</sup>

This results in severely injured or disabled young people having to fight protracted legal battles in order to obtain access to insurance funds to fund rehabilitation, disability support and housing.

5.43 In its submission, Suncorp, the nation's leading personal injury insurer, highlighted the complementary nature of the NDIS and the NIIS:

The intended purpose of the NDIS is to offer individualised care and support for those with significant disabilities acquired from a medical condition or birth defect on a needs basis. Complementing NDIS and the statutory schemes, the NIIS is to offer individualised care and supports on a needs basis for those with significant disabilities arising from a traumatic event or accident.<sup>40</sup>

5.44 The committee received evidence from Associate Professor Andrew Way of Alfred Health crediting best practice statutory personal injury schemes as found in Victoria:

I am giving credit to the Transport Accident Commission here and the Victorian WorkCover Authority, who take ongoing responsibility for their clients post injury. What we see is a quite different response, because they have a different financial interest. So their response has been around whole-life-cycle costs for the individual, with the individual making the choices. They will create packages of care, opportunity for residences and so on—all the things that we have been talking about—because it is in their financial interest to do so.<sup>41</sup>

5.45 As part of these statutory schemes viewing whole of life-cycle costs to the individual, there should be a focus on early investment to ensure a young person is able to regain independence early. Suncorp noted that:

A best practice personal injury scheme is essentially one that fosters early social and financial independence, which in turn is likely to have a positive impact on workforce participation and economic growth in Australia. This

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39 Australian Government, The Treasury, *National Injury Insurance Scheme—Consultation Regulation Impact Statement*, p. 1, <http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2015/NIIS%20Workplace%20Accidents/Key%20Documents/PDF/NIIS-RIS-03-2015.ashx> (accessed 12 June 2015).

40 Suncorp, *Submission 100*, p. 2.

41 Associate Professor Andrew Way, Chief Executive Officer, Alfred Health, *Committee Hansard*, Melbourne, 11 March 2015, p. 7.

requires a holistic and seamless public policy approach, which does not currently exist.<sup>42</sup>

5.46 Currently, the NIIS is in the early stages of development, with The Treasury conducting a consultation period with stakeholders and the general public. The committee recognises the need for a national, 'no-fault' statutory personal injury scheme.<sup>43</sup> This national scheme should ensure that young people involved in catastrophic workplace or motor vehicle accidents can fund early intervention rehabilitation and transition to appropriate accommodation and supports.

### ***Committee view***

5.47 The committee acknowledges that the NDIS is currently in a trial phase and is developing policy on a wide range of issues as feedback is received from the trial sites. Although there is a great deal of optimism about the possibilities and opportunities the NDIS presents, there is also concern around a number of key areas where further policy development is required. It is the committee's view that the Commonwealth Government—through DSS and the NDIA—need to accept a lead role in the provision of specialised disability housing, key workers and delivery of the NIIS.

### **Subsequent developments and current support options for young people with a disability**

5.48 Since the conclusion of the YPIRAC program, there have been a number of developments relating to young people in residential care in each of the states and territories. These are examined below.

#### ***New South Wales***

5.49 After the conclusion of YPIRAC, an interagency steering committee in NSW developed the framework *Care and Support Pathways for People with an Acquired Brain Injury: Referral and Service Options in NSW*. This brought together contributions from key state agencies and represented a best practice framework for provision of support and housing for young people with traumatic brain injury (TBI) or acquired brain injury (ABI).

5.50 The framework states that support for young people with a TBI or an ABI can follow a number of typical pathways. In many cases, there are supports in place to move young people with such injuries from hospital to being supported in their own home. These cases generally are those where less than 35 hours of support per week is required, and where an individual does not present with challenging behaviours or a complicated background such as release from prison or an undiagnosed ABI/TBI.

5.51 For those people who require more than 35 hours per week of care, it is possible to be supported either at home or in supported accommodation. In some

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42 Suncorp, *Submission 100*, p. 2.

43 Australian Government The Treasury, *National Injury Insurance Scheme—Workplace Accidents*, <http://www.treasury.gov.au/ConsultationsandReviews/Consultations/2015/NIIS-Workplace-Accidents>, (accessed 12 June 2015).

cases, a person may be referred to live in a RACF. However, the NSW Department of Family and Community Services stipulates that 'this is not a suitable option, especially if [the] client is a younger person and they do not require 24/7 support. All other options should be exhausted before referral to RACF is seriously considered'.<sup>44</sup>

5.52 Young people with a disability are eligible for access to the Home and Community Care (HACC) services that help 'people with disability to remain at home and prevent their inappropriate or premature admission to residential care'. Services include help with household chores, health and personal care, activities and transport, short breaks, and home maintenance and modification.<sup>45</sup> Similar services are available through the Home Care Service (HCS). Both HACC and HCS are largely operated by the non-government sector funded by Commonwealth and state contributions.

5.53 The committee acknowledges the comprehensive nature of this framework, but expresses concern that 'to date, there is no implementation plan for the NSW framework'.<sup>46</sup>

### ***Western Australia***

5.54 In its submission, the Brightwater Care Group has provided two flow charts that outline the process by which people with a disability can access support. These processes are outlined in Figure 5.1 and 5.2 below.<sup>47</sup> It is important to note that when people with disabilities are either known or referred to the Disability Services Commission (DSC), other support and accommodation options are explored before RACF is considered. However, if the DSC is not aware of or involved in the assessment, it is possible for a GP or social worker to refer a person with disability directly to an Aged Care Assessment Team (ACAT).<sup>48</sup> This can result in a young person being placed in a RACF without other options being considered.<sup>49</sup> Despite the presence of these pathways, it is still possible for individuals to fall between the cracks and risk inappropriate placement in a RACF.

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44 Department of Family and Community Services (Ageing, Disability and Home Care), *Care and Support Pathways for People with an ABI: Referral and Service Options in NSW*, pp 3–9, May 2011. [http://www.adhc.nsw.gov.au/\\_data/assets/file/0007/237751/ADHC-ABIPathways-R10.pdf](http://www.adhc.nsw.gov.au/_data/assets/file/0007/237751/ADHC-ABIPathways-R10.pdf) (accessed 22 January 2015).

45 Department of Family and Community Services (Ageing, Disability and Home Care), *Home and Community Care services*. [http://www.adhc.nsw.gov.au/individuals/help\\_at\\_home/home\\_and\\_community\\_care\\_services](http://www.adhc.nsw.gov.au/individuals/help_at_home/home_and_community_care_services) (accessed 23 January 2015). This service is available to those with a 'moderate, severe or profound disability or [those] caring for someone with a disability'.

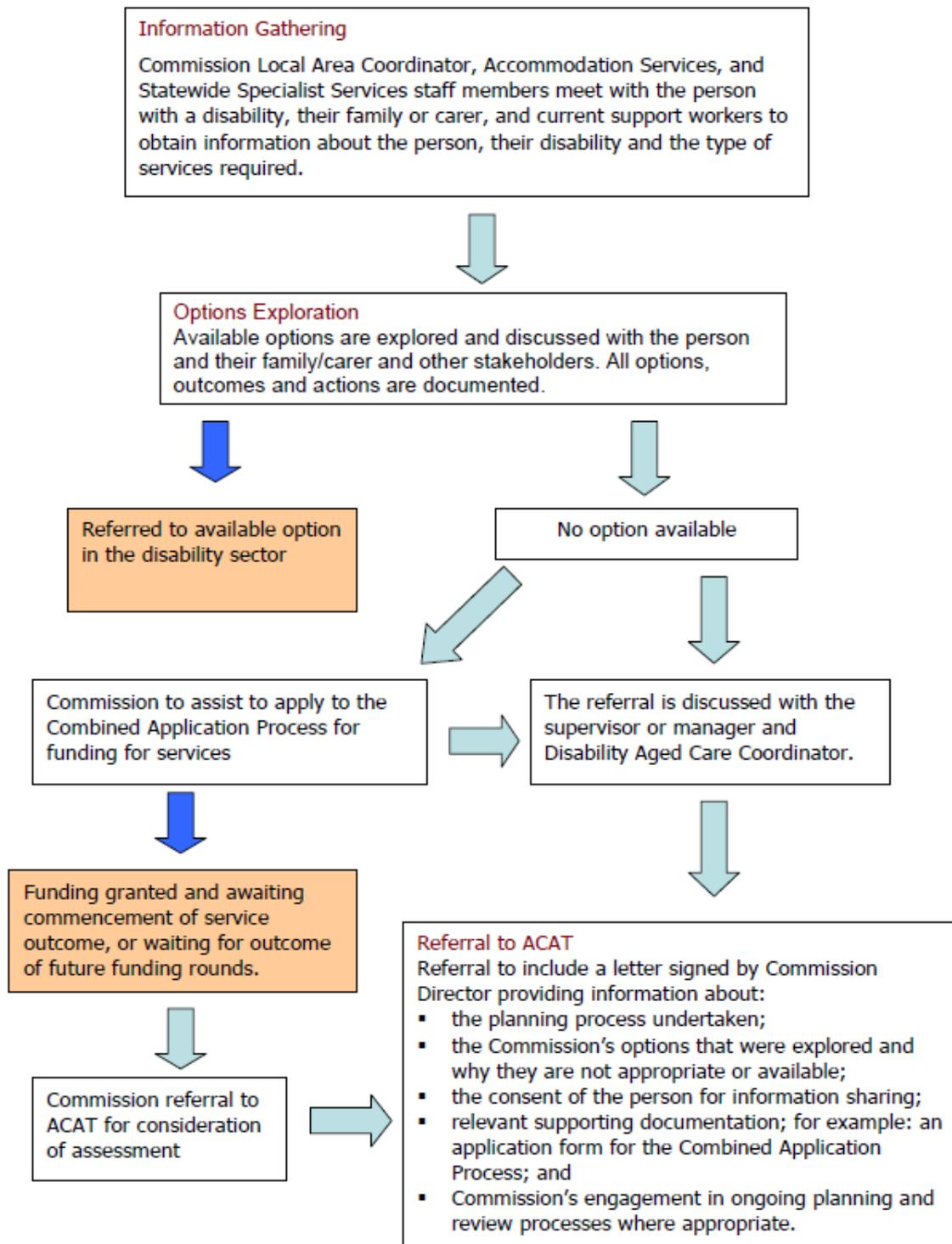
46 NSW Council for Intellectual Disability, *Submission 75*, p. 3.

47 Brightwater Care Group, *Submission 115*, pp [23–24].

48 Referral to an ACAT can also be undertaken by hospital doctors, medical specialists, self-referral by the young person themselves, their family, carer, community worker or community agency.

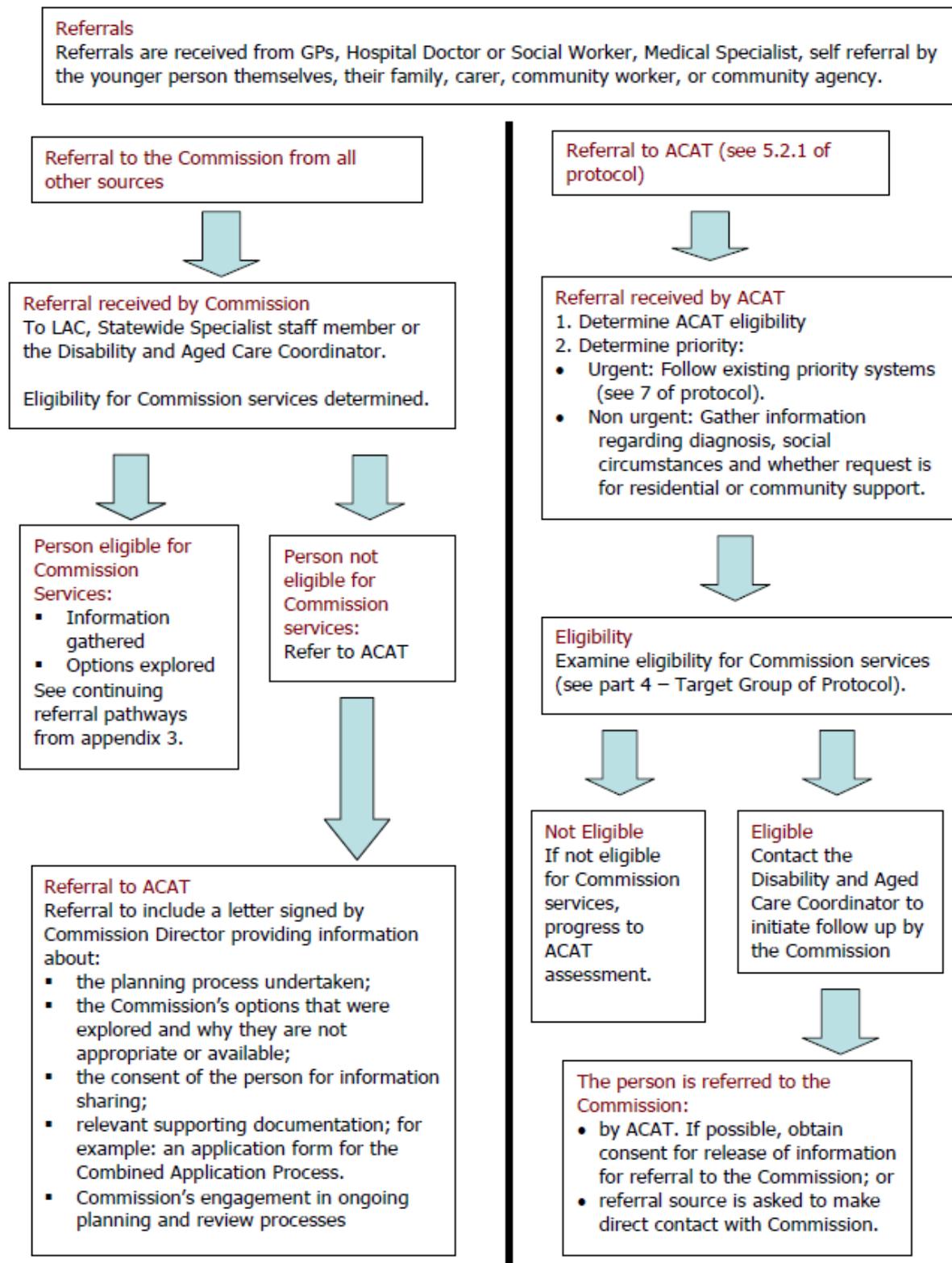
49 Brightwater Care Group, *Submission 115*, pp [15–27].

**Figure 5.2: Process for support assessment options for young people with a disability who are known to the DSC**



Source: Brightwater Care Group, *Submission 115*, p. [23].

**Figure 5.3: Process for support assessment for young people with a disability not known to the DSC**



Source: Brightwater Care Group, *Submission 115*, p. [24].

5.55 As discussed in Chapter 4, Western Australia have a number of:

[L]ocal area coordinators employed by the Disability Services Commission regularly liaises with social workers in that hospital setting.<sup>50</sup>

5.56 Whilst this initiative is commendable, the committee received a range of evidence suggesting that these positions were not meeting the expectations of the disability sector.<sup>51</sup>

### ***South Australia***

5.57 The South Australian Government Department for Communities and Social Inclusion made a submission to the inquiry and appeared at the public hearing in Darwin. In an answer to a question on notice, the department noted its Accommodation Placement Panel:

Since the conclusion of the former national Younger People In Residential Aged Care (YPIRAC) initiative, the South Australian Government has maintained a strong commitment to supporting younger people with disability to move from residential aged care into more appropriate disability supported accommodation, where that is their choice.

Within the Department for Communities and Social Inclusion, an Accommodation Placement Panel exists as a central point for registering and reporting all nominated supported accommodation vacancies across South Australia. The Panel prioritises and matches referred eligible people with disability to these vacancies.

All people with disability under 65 years of age (under 50 years of age for Aboriginal and Torres Strait Islander people) living in residential aged care facilities, who wish to move to alternative community accommodation, are accorded the highest priority by the Accommodation Placement Panel and matched with suitable accommodation vacancies when they become available.

The work of the Panel has a strong focus on proactive, person-centred planning in partnership with the person with disability, their family and carers.<sup>52</sup>

### ***Tasmania***

5.58 In its submission to the committee, the Tasmanian Government noted:

Since the conclusion of YPIRAC in 2011, Tasmania has continued to use YPIRAC principles and guidelines to ensure that younger people can be

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50 Dr Ron Chalmers, Director-General, WA Disability Services Commission, *Committee Hansard*, Perth, 17 February 2015, p. 31.

51 See: Mrs Caroline Watt, Executive Director, Operations, Nulsen Disability Services, *Committee Hansard*, Perth, 17 February 2015, p. 40. See also: Ms Tracy Foulds, Executive Officer, Headwest, *Committee Hansard*, Perth, 17 February 2015, p. 9.

52 Answer to question taken on notice, South Australian Department of Communities and Social Inclusion, p. 3,  
[http://www.apf.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Young\\_people\\_in\\_aged\\_care/Additional\\_Documents](http://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents) (accessed 10 June 2015).

diverted from residential aged care where possible. However as the YPIRAC initiative highlighted, there is a significant challenge in providing appropriate accommodation and support pathways for younger people with complex health care needs.

In Tasmania, appropriate and affordable housing supply continues to be one of the most significant challenges for people with disability; there is a shortage of alternative accommodation and providers geared to deliver the level of intensive, complex supports often required by this cohort to maintain more independent living arrangements. There are various factors which contribute to this challenge including:

- insufficient support for residents' medical requirements in non-institutional settings, particularly at night;
- gaps in the staff knowledge and training needs required for disability care, as distinct from aged care;
- lack of alternate accommodation options for those wishing to remain in their community;
- the high cost of care for people with complex physical and neurological disabilities; and
- the differences in support approaches for aged care versus independent living.<sup>53</sup>

5.59 During the Hobart hearing, Ms Ingrid Hanley of the Department of Health and Human Services highlighted one measure that has successfully diverted many young people from aged care:

[P]art of that is that we have established a really good working relationship with our colleagues in the acute hospital settings in our three regional hospitals. So we meet quite regularly with the hospitals to go through who has been admitted into the hospital system and is at risk of being discharged into inappropriate accommodation unless we can work out a support package for those individuals.<sup>54</sup>

5.60 Dr Bronwyn Morkham also noted that:

Since YPIRAC only one state, Tasmania, has made its Aids and Equipment Program available to young people living in residential aged care.<sup>55</sup>

## **Victoria**

5.61 The Victorian Government established the 'My Future My Choice' initiative at the conclusion of the YPIRAC program in 2011. This program presented opportunities for many young people in aged care to move to more appropriate

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53 Tasmanian Government, *Submission 118*, pp [1–2].

54 Ms Ingrid Hanley, Director, Disability and Community Services, Department of Health and Human Services, *Committee Hansard*, Hobart, 12 March 2015, p. 16.

55 Dr Bronwyn Morkham, National Director, Young People living in Nursing Homes National Alliance, *Committee Hansard*, Sydney, 19 February 2015, pp 28–29.

supported accommodation environments. However, once these places became full there has been extremely limited access to new people requiring that level of supported accommodation. This is due to the long life expectancy of young people with permanent disabilities. New and ongoing capital development and funding support is needed to support continued growth in these types of alternative housing for people with complex care needs.<sup>56</sup>

### **Committee view**

5.62 This chapter has noted the Commonwealth and state government response to the issue of young people living in residential care since 2006. The committee accepts that the YPIRAC program was a useful starting point and was successful in reducing the number of under 50s living in residential aged care. However, the numbers of 50–64 year olds—nearly 90 per cent of young people living in residential care—remains largely unchanged. The key reason this scheme failed was lack of specialised disability accommodation.

5.63 The committee recognises that since the end of YPIRAC, some states—particularly South Australia and Tasmania—have continued to implement the YPIRAC principles when delivering services and support to this cohort. However, other jurisdictions, including those with larger populations of young people living in RACF do not appear to be adopting a targeted approach. It is the committee view that without strong Commonwealth leadership, the diversion and exit of young people from residential care will not occur.

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56 Mrs Joan D'Abreo, *Submission 8*, p. [2]. Joan's husband, John was offered a place in one of the pilot shared supported accommodation facilities. See also: Mr Stephen Naughtin, *Submission 23*, pp [2–3]. Stephen's son, Ryan, was offered a *My future, my choice* placement. This involved him having to move from his home in Bendigo to supported accommodation in Melbourne where he was distant from family and his condition regressed. Although the placement was not suitable, he could not move without forfeiting the funding associated with the placement. This account highlights the need for flexibility in the funding and location of these placements.

# Chapter 6

## Conclusion and Recommendations

### Introduction

6.1 Throughout the inquiry, the committee has been presented with evidence—including many personal accounts—that details why residential care is inappropriate for young people aged under 65 years. The committee notes that this is not a new issue. In 2005, this committee conducted an inquiry into *Quality and equity in aged care* which highlighted the inappropriateness of young people living in residential aged care facilities (RACF). The *Quality and equity in aged care* inquiry recommended that all jurisdictions work together to ensure that no further admissions occurred and that young people currently in RACF be transitioned out.

6.2 The Younger People with Disability in Residential Care (YPIRAC) program was established as a result of this recommendation, and operated from 2006 until 2011 with the program ceasing due to the discontinuation of the state's funding contribution. The Commonwealth continues to contribute the funding allocated for YPIRAC to the states, although this funding is not tied to any particular program. The YPIRAC initiative was effective as a 'first step' by reducing the numbers of under 50 year olds living in RACF, whilst the 50–64 year old cohort—who make up nearly 90 per cent of young people living in RACF—has increased. Ten years on from the *Quality and equity in aged care* inquiry, the total number of young people living in RACF remains largely unchanged.

6.3 The committee notes that this current inquiry has been conducted during a transition period as the National Disability Insurance Scheme (NDIS) is phased in. This period of transition is characterised by profound changes to the way disability services are administered and delivered by the states and the Commonwealth. The committee recognises the importance of transitioning disability funding and services towards a person-centred model; however, notes that there is a lack of clarity around the delivery of certain services using this model. For example, it is unclear how capital is to be provided to build the 'bricks and mortar' of specialised disability accommodation. It is the committee's view that young people living in residential care have waited too long and cannot continue to wait for policy development to improve their lives during this transition period.

6.4 This inquiry has established the importance of providing co-ordinated services to this cohort and highlighted the role of integrated services that take into account an individual's needs at different stages of their recovery or disability. It is critical that these support services are provided for individuals whether they live in hospital, in the community or in aged care. Transition into appropriate accommodation is predicated on the 'need for people with disabilities to be provided with specialised assistive therapeutic and rehabilitation services and technology'.<sup>1</sup> It is also predicated on the

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1 Brotherhood of St Lawrence, *Submission 59*, p. [6].

availability of suitable accommodation options. Collaboration between the state, territories and the Australian Government is critical in meeting the needs of this group of young Australians. It is the committee view that there is a need for both a co-ordinated national approach and proactive action by the states and territories.

6.5 This chapter draws together a number of recommendations that are directed at three key groups—the Australian Government, the Joint Standing Committee on the National Disability Insurance Scheme and the Council of Australian Governments.

### **Recommendations to the Australian Government**

6.6 The lack of up to date and detailed statistical data available on young people living in RACF has been noted throughout the inquiry. Where this data does exist, it is not always readily available to those that require access including many individuals, service providers and government agencies. The committee has noted the lack of available information on unmet need. This information is required not only in the short term, but also in the longer term to allow governments at all levels to plan for the expected increased demand for disability support services and accommodation in the future.

#### **Recommendation 1**

**6.7 The committee recommends that the Australian Government compile a database of all young people under the age of 65 years living in residential aged care facilities using the data held by the Aged Care Assessment Team (ACAT) program. This list should be provided in a regularly updated form to the National Disability Insurance Agency (NDIA) and to state and territory governments. This data should include the following information:**

- **name;**
- **age and age of entry to aged care;**
- **diagnosis;**
- **length of time spent in the aged care system; and**
- **the factors that need to be addressed for the person to move out of the aged care facility.**

#### **Recommendation 2**

**6.8 The committee recommends that the Australian Bureau of Statistics (ABS) conduct a Longitudinal Survey of Disability, Ageing and Carers in addition to its triennial survey of Disability, Ageing and Carers.<sup>2</sup>**

6.9 The committee makes the following recommendation to establish a standardised national approach to the assessment and placement of young people. The establishment of a comprehensive assessment and placement tool utilised within the health and disability sectors is a first step in ensuring that a young person's needs are

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2 See Chapter 2.

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clearly identified and understood by young people, their families, and state and Commonwealth Governments.

### **Recommendation 3**

**6.10 The committee recommends that the Australian Government develop and implement a comprehensive assessment and placement tool or residential assessment instrument to assess the care and accommodation needs for all young people living in or at risk of entering residential care.<sup>3</sup>**

6.11 In addition to the establishment of the comprehensive assessment and placement tool, the committee recognises the need for effective safeguards to ensure the effective diversion from, and exit of young people from RACF. The committee also recognises the need to ensure that those living in RACF are provided with supports to choose the most appropriate accommodation option.

### **Recommendation 4**

**6.12 The committee recommends that supplementary assessment guidelines and tools are developed for the ACAT program to ensure that all young people being considered for an aged care placement are properly assessed. As part of this process, the committee recommends that:**

- all young people placed in aged care are intensively case managed; and
- all ACAT placements for those aged under 65 are reviewed on an annual basis.<sup>4</sup>

### **Recommendation 5**

**6.13 The committee recommends that the accreditation standards for residential aged care are amended to include standards relating to the clinical outcomes and lifestyle needs of young people. In order to assist with meeting these new accreditation standards, the committee recommends that the Australian Government:**

- provide a supplementary payment to residential aged care facilities to ensure that these accreditation standards can be met; and
- invest in disability specific training for all staff involved in the care of young people living in aged care. This training should focus on building improved awareness of the needs of young people and those living with disability in order to provide better support. It should also lead to improved connectivity between the aged care sector and other service sectors including allied health and disability services.<sup>5</sup>

6.14 This inquiry has received evidence highlighting the undersupply of specialised disability accommodation (SDA). This undersupply of SDA is noted as the

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3 See Chapter 4.

4 See Chapter 4.

5 See Chapters 3 & 4.

primary reason that the YPIRAC initiative was not as successful as it could have been. The committee notes that young people cannot be diverted or exited from residential facilities if there is nowhere for them to go.

6.15 The role of the NDIS, the Commonwealth and the states in the provision of funding for SDA is unclear with the committee receiving contradictory evidence from the Commonwealth on this matter. This confusion and uncertainty extends to individuals, their families and service providers. There have been a range of innovative housing solutions presented to the committee; however, without clarity around the funding mechanisms, it is uncertain how or if they will ever be built.

6.16 The committee acknowledges that the Commonwealth and the states are currently seeking to broker a series of bi-lateral agreements and provide certainty around this issue in the near future. However, it is the committee's view that a source of capital for SDA should be made available as an interim measure to ensure that the supply of SDA is increased during this time.

### **Recommendation 6**

**6.17 The committee recommends that the Department of Social Services' current discussion paper on disability housing consider capital funding options for construction of specialised disability accommodation.<sup>6</sup>**

**6.18 The committee recommends that the discussion paper is released as a matter of urgency.**

**6.19 The committee recommends that the Australian Government establish a supported disability accommodation fund similar to the Supported Accommodation Innovation Fund.<sup>7</sup>**

### **Recommendations to the Joint Standing Committee on the National Disability Insurance Scheme**

6.20 The issue of specialised disability housing is critical to the success of the NDIS. The committee makes the following recommendation to ensure a focus remains on this issue.

### **Recommendation 7**

**6.21 The committee recommends that the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) conduct an inquiry into the issue of disability housing after the release of the discussion paper on disability housing.**

### **Recommendations to the Council of Australian Governments (COAG)**

6.22 The committee notes the importance of the provision of rehabilitation health services including speech pathology, physiotherapy and occupational therapy in promoting recovery and independence in young people with severe disability. There is

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6 See Chapters 4 & 5.

7 See Chapters 4 & 5.

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a need for a coherent national plan to deliver rehabilitation programs including slow stream rehabilitation.

### **Recommendation 8**

**6.23 The committee recommends that the COAG develop and implement a national rehabilitation strategy including a framework for the delivery of slow stream rehabilitation in all jurisdictions.<sup>8</sup>**

6.24 Young people with complex needs require access to a range of specialist disability and mainstream services. The committee has received significant evidence demonstrating that many of these departments and agencies work as 'silos', and fail to provide adequate and appropriate services resulting in young people falling between the cracks. As a result of this, many of these young people have and will continue to be moved into residential care. It is the committee's view that this is unacceptable.

6.25 Cross sector co-ordination where 'coordinators actively negotiat[e] between sectors and services to ensure people obtain the necessary supports' is the only way in which young people can be assured of being provided with adequate health, rehabilitation and housing supports.<sup>9</sup>

6.26 This inquiry has also highlighted the need for advocates to assist young people with information and decision-making throughout their journey. The committee has heard evidence noting the lack of information available when a diagnosis is made with young people often being forced to make uninformed decisions that often lead to them living in a RACF. Advocates can help guide and inform a young person—and agencies—on the range of support and accommodation options to enable a young person to make the best decision for their transition and placement. Advocates can also assist with complaints resolution and 'speaking out' and act on behalf of a young person.

6.27 The committee notes that the YPIRAC initiative sought to achieve three objectives—to exit those living in RACF, to divert those young people at risk of entering RACF, and to enhance the delivery of specialist services for those choosing to remain in RACF. The committee also notes that the states no longer have dedicated funding for this initiative, whilst the Commonwealth has continued to contribute its share. It is the committee's view that this funding—approximately \$25 million per year—should be used to partially fund the three recommendations below which seek to achieve the same objectives as the YPIRAC initiative. The committee recognises that jurisdictional responsibility is split based around locations of the NDIS trial sites. The Commonwealth has jurisdiction in the NDIS trial sites whereas state and territory

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8 See Chapter 4.

9 Centre for Disability Research and Policy, University of Sydney (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA) 2014. *Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge*, p. 1, <http://sydney.edu.au/health-sciences/cdrp/discussion-paper-complexneeds-july2014.pdf> (accessed 25 May 2015).

governments retain jurisdiction for the rest of their respective states and territories until the NDIS is fully phased in.

### **Recommendation 9**

**6.28 The committee recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas:**

- **assign an advocate to all young people living in residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person;**
- **assign an advocate to all young people at risk of entering residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person. The advocate should be made available as early as possible after diagnosis of an illness or disability and be assigned before any placement commences;**
- **extend the National Younger Onset Dementia Key Worker Program (YODKWP) to all young people identified as being at risk of placement in residential care to provide collaborative case management.<sup>10</sup> The key worker should be assigned before any placement commences; and**
- **these programs should be proactively extended to young people living in residential care facilities under the age of 65 years by June 2017. Consideration of the mental health status of young people should be prioritised with appropriate support provided where necessary.**

6.29 The committee recommends the following for those with Foetal Alcohol Spectrum Disorder (FASD).

### **Recommendation 10**

**6.30 The committee recommends that the NDIS, in all NDIS trial sites, should consider how it supports those with Foetal Alcohol Spectrum Disorder (FASD).**

**6.31 The committee also recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas work closely with community health services to provide the following for those with FASD**

- **agreement on a standardised diagnostic tool; and**
- **provision of early intervention services and other health services such as speech pathology, physiotherapy and occupational therapy.<sup>11</sup>**

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10 See Chapters 3, 4 & 5.

11 See Chapter 4.

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## **Recommendation 11**

**6.32** The committee recommends that the COAG establish a joint taskforce for young people living in residential care. This taskforce will:

- facilitate the development and implementation of integrated service pathways involving a range of portfolios at a state and federal level including housing, health, aged care, disability, and transport; and
- facilitate the collation and development of information packs outlining support, transition and placement options for young people. These packs should be made available to young people, their families, health practitioners and other relevant professionals in hospitals and aged care facilities. This process should collate all information and tools developed by the states during the Younger People with Disability in Residential Aged Care (YPIRAC) program and lead to the development of a standardised national information pack and make available to all state and territory governments for deployment.

**6.33** The joint taskforce will also be responsible for oversight of the following for young people living in a Residential Aged Care Facility (RACF):

- access to appropriate prescribed specialist services including speech pathology, physiotherapy, occupational therapy and other allied health services;
- the national rehabilitation strategy;
- the provision of advocates;
- the expanded key worker program;
- access to fully funded equipment as part of all state and territory Aids and Equipment schemes;
- a cross sector approach is adopted to explore options for the provision of short term respite services; and
- that all young people who indicate that they do not wish to live in residential care are transitioned into appropriate alternate accommodation by June 2018.<sup>12</sup>

## **Recommendation 12**

**6.34** The committee recommends that the joint taskforce issues a half yearly report on the progress of Recommendation 11 to the COAG.

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12 See Chapter 4.

**Senator Rachel Siewert**  
**Chair**

# **APPENDIX 1**

## **Submissions and additional information received by the Committee**

### **Submissions**

- 1** Independent Advocacy Townsville (plus a supplementary submission)
- 2** Ms Geraldine Colson
- 3** Professor Brian Draper
- 4** Ms Maddy Archer
- 5** Mr Peter Szentirmay
- 6** Ms Kirrily Hayward (plus a supplementary submission)
- 7** Ms Heather Dare
- 8** Ms Joan D'Abreo
- 9** Mrs Dianne Marshall
- 10** Mr Chris Le Cerf
- 11** Ms Rhonda Danylenko
- 12** Community Safeguards Coalition (plus an attachment)
- 13** Mrs Leona Jones
- 14** Name Withheld
- 15** Name Withheld
- 16** Ms Vicky Smith
- 17** Greystanes Disability Services
- 18** Dr Peter Gibilisco
- 19** Ms Katy Skene
- 20** Mr James Nutt
- 21** Mr Daniel Black
- 22** Name Withheld

- 23 Mr Stephen Naughtin
- 24 Ms Lyne Merrick
- 25 Mrs Karen Higgins
- 26 Queensland Family and Child Commission
- 27 Ms Sam Petersen
- 28 Ms Sarah Ryan
- 29 Name Withheld
- 30 Mr James Bailey
- 31 Mr Gordon and Mr Jim
- 32 Ms Bev Shalders
- 33 The Salvation Army National Secretariat
- 34 Name Withheld
- 35 Mrs Dorothy Bussell
- 36 Mr Greg Brown
- 37 Mrs Vicki Brous (plus a supplementary submission)
- 38 Ms Julie Pianto (plus a response from E.W. Tipping Foundation)
- 39 Disability Council NSW
- 40 Mrs Ann Newland
- 41 Name Withheld
- 42 Families Australia
- 43 Leading Age Services Australia Ltd
- 44 Mrs Lauren Bellert
- 45 Focus ACT
- 46 MS Australia
- 47 Disability Justice Advocacy Inc.
- 48 Down Syndrome Victoria
- 49 Mr and Mrs Colin and Leonie Brodie

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- 50** The Royal Australian and New Zealand College of Psychiatrists
- 51** Ms Kathleen Cameron (plus a supplementary submission)
- 52** Mr Ben Thompson
- 53** Australian Catholic Bishops Conference
- 54** Name Withheld
- 55** Department of Social Services
- 56** Confidential
- 57** Alzheimer's Australia
- 58** Catholic Health Australia
- 59** Brotherhood of St Laurence
- 60** Alzheimer's Australia NSW
- 61** Mrs Anita Geach-Bennell
- 62** Youth Disability Advocacy Service
- 63** Confidential
- 64** Mr Denis Cavanagh
- 65** Multiple Sclerosis Ltd (plus five attachments)
- 66** Ms Jennifer Nolan
- 67** Australian Human Rights Commission
- 68** Catholic Women's League Australia Inc.
- 69** Australian Association of Developmental Disability Medicine
- 70** Northcott
- 71** Mr Terry and Mr Darrell Bainbridge
- 72** Mr Chris Anastasiou
- 73** Aged and Community Services Australia
- 74** Mrs Helen Barker (plus three attachments)
- 75** NSW Council for Intellectual Disability
- 76** Office of the Public Guardian Queensland

- 77 Australian Bureau of Statistics (plus an attachment)
- 78 Melba Support Services
- 79 Australian Huntington's Disease Association
- 80 CREATE Foundation
- 81 Carers and Parents Support Group Inc.
- 82 Inability Possability Inc.
- 83 Combined Pensioners and Superannuants Association
- 84 Ms Yvonne Kromkamp
- 85 Ms Jane Thomas
- 86 Mr and Mrs Kev and Lyn Isaacs
- 87 HammondCare
- 88 Mr Rick van de Paverd
- 89 NSW HACC Development Officers Network
- 90 National Disability Services
- 91 Queensland Advocacy Incorporated
- 92 QADA
- 93 Young People In Nursing Homes National Alliance (plus three attachments)
- 94 Australian Home Care Services
- 95 Visionary Design Development Pty Ltd
- 96 MS Queensland
- 97 Name Withheld
- 98 Name Withheld
- 99 Ms Sally Korbel
- 100 Suncorp
- 101 Parkinson's Western Australia
- 102 Children with Disability Australia (plus an attachment)

- 103 Headwest
- 104 Carers NSW
- 105 Australian Psychological Society
- 106 Mrs Keryn Hickey
- 107 Ms Vicki Wilkinson
- 108 Name Withheld
- 109 Summer Foundation
- 110 Office of the Public Advocate Victoria
- 111 Ms Nicole Everingham
- 112 Mrs Sue Hodgson
- 113 NSW Public Guardian
- 114 Ms Sharon Jacobs
- 115 Brightwater Care Group
- 116 JacksonRyan Partners
- 117 Brain Injury Association of NSW (plus six attachments)
- 118 Tasmanian Government
- 119 Name Withheld
- 120 Ms Una Harrington
- 121 National Complex Needs Alliance (plus an attachment)
- 122 MacKillop Family Services
- 123 Motor Neurone Disease Australia
- 124 UnitingCare Australia
- 125 Physical Disability Council of NSW
- 126 Confidential
- 127 Huntington's WA
- 128 Disability Advocacy Network Australia Ltd
- 129 Ms Pauline Nutley

- 130 Baptistcare Inc WA
- 131 ACT Disability, Aged and Carer Advocacy Service Inc
- 132 Catholic Social Services Victoria
- 133 Australian Lawyers for Human Rights
- 134 Office of the Public Advocate Queensland
- 135 Ms Mary Haebien
- 136 National Rural Health Alliance
- 137 Alfred Health
- 138 Name Withheld
- 139 Mrs Mary Nolan (plus two attachments)
- 140 ACT Government
- 141 Australian Institute of Health and Welfare
- 142 Victorian Coalition of ABI Service Providers Inc
- 143 JFA Purple Orange
- 144 Wesley Mission Victoria
- 145 Ms Kathryn Bruce
- 146 Occupational Therapy Australia
- 147 People with Disability Australia (plus two attachments)
- 148 Life Without Barriers (plus two attachments)
- 149 Mr Nick Kehaidis
- 150 Queensland Law Society
- 151 NSW Disability Network Forum
- 152 Ms Marina Nikolova
- 153 Department of Developmental Disability Neuropsychiatry
- 154 Youngcare
- 155 Melbourne City Mission
- 156 Ms Jan Barham

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- 157** Government of South Australia
- 158** Developmental Disability WA and People With disabilities WA
- 159** Karingal
- 160** L'Arche Australia
- 161** Confidential
- 162** Lifestyle in Supported Accommodation Inc
- 163** Mrs Janet Mitchell and Mrs Juana Fernandez
- 164** Anglicare Australia
- 165** Ms Estelle Shields
- 166** Federation of Ethnic Communities' Councils of Australia
- 167** Hall and Prior

### **Additional Information**

- 1** The Future of Housing for Older Australians, Position Paper, January 2015, from Aged and Community Services Australia, received 19 February 2015
- 2** Additional comments, from Wesley Mission Victoria, received 29 March 2015
- 3** Further information after appearance at Hobart public hearing, from Mt St Vincent Home, received 30 March 2015
- 4** Supplementary information, from Alzheimer's Australia, received 10 April 2015
- 5** Submission to the Productivity Commission's Inquiry into Disability Care and Support, by Young People In Nursing Homes National Alliance, September 2010, from Young People In Nursing Homes National Alliance, received 25 May 2015
- 6** CLO/DSO/Plan Management Providers - summary points, from Young People In Nursing Homes National Alliance, received 25 May 2015

- 7 Response to the Productivity Commission's Draft Report into Disability Care and Support, by Young People In Nursing Homes National Alliance, May 2011, from Young People In Nursing Homes National Alliance, received 25 May 2015

### **Answers to Questions on Notice**

- 1 Answers to Questions taken on Notice during 11 March public hearing, received from Multiple Sclerosis Ltd, 30 March 2015
- 2 Answers to Questions taken on Notice during 11 March public hearing, received from Multiple Sclerosis Ltd, 30 March 2015
- 3 Answers to Questions taken on Notice during 12 March public hearing, received from Tasmanian Department of Health and Human Services, 14 April 2015
- 4 Answers to Questions taken on Notice during 1 April public hearing, received from South Australian Government, 28 April 2015
- 5 Answers to Questions taken on Notice during 15 May public hearing, received from Australian Institute of Health and Welfare, 29 May 2015
- 6 Answers to Questions taken on Notice during 15 May public hearing, received from Australian Bureau of Statistics, 3 June 2015
- 7 Answers to Questions taken on Notice during 15 May public hearing, received from National Disability Insurance Agency, 4 June 2015
- 8 Answers to Questions taken on Notice during 15 May public hearing, received from Department of Social Services, 10 June 2015
- 9 Answers to Questions taken on Notice during 15 May public hearing, received from Department of Social Services, 18 June 2015

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## Correspondence

- 1 Correspondence from Dr Ron Chalmers of the WA Disability Services Commission, received 8 April 2015
- 2 Correspondence clarifying evidence given at Canberra public hearing on 15 May, from the Department of Social Services, received 22 May 2015

## Tabled Documents

- 1 Oats Street Facility Redevelopment—A Social Cost-Benefit Analysis, tabled by Brightwater Care Group, at Perth public hearing 17 February 2015
- 2 Opening statement, tabled by Ms Kirstine Bruce, at Perth public hearing 17 February 2015
- 3 Opening statement, tabled by Mr Norman de Wet, at Perth public hearing 17 February 2015
- 4 Opening statement, tabled by First Peoples Disability Network (Australia), at Sydney public hearing 19 February 2015
- 5 Statewide Progressive Neurological Disease Project, tabled by Multiple Sclerosis Ltd, at Melbourne public hearing 11 March 2015
- 6 Findings from the Summer Foundations 'NDIS Connections' Program, tabled by Summer Foundation, at Melbourne public hearing 11 March 2015
- 7 Freedom Housing versus Traditional Models of Care and Accommodation For Persons with Disabilities: A structured comparative analysis evaluating the models' degree of compatibility with the relevant Objects and Principles of the NDIS Act 2013, tabled by Mr Christos Iliopoulos, at Melbourne public hearing 11 March 2015
- 8 Freedom Housing Concept Drawing, tabled by Mr Christos Iliopoulos, at Melbourne public hearing 11 March 2015
- 9 Rowallan Park Intentional Community booklet, tabled by Uniting Church in Australia, at Hobart public hearing 12 March 2015

- 10** Response to the inquiry, tabled by L'Arche, at Hobart public hearing  
12 March 2015
  
- 11** National Disability Insurance Scheme, The Trial in the Barkly, tabled by  
Anyinginyi Health Aboriginal Corporation, at Darwin public hearing  
1 April 2015

## **APPENDIX 2**

### **Public hearings**

*Tuesday, 17 February 2015*

*Pan Pacific Hotel, Perth*

#### **Witnesses**

##### **Brightwater Care Group Inc.**

LAWRENCE, Ms Jennifer, General Manager, Disability, Research and Risk

WAGLAND, Mrs Janet, Manager, Services for Younger People

##### **Headwest, Brain Injury Association of WA**

FOULDS, Ms Tracy, Executive Officer

##### **BRUCE, Ms Kirstine Elizabeth, Private capacity**

##### **Multiple Sclerosis Society WA**

PALMER, Mrs Gail Veronica, Manager, Community Programs

##### **People With Disabilities WA Inc.**

JENKINSON, Ms Samantha May, Executive Director

PRATTS-HINCKS, Mrs Carmen, Senior Advocate

WRIGHT, Ms Christina Anne, Individual Advocate

##### **de WET, Mr Pierre Norman, Private capacity**

##### **REEDY, Ms Carolyn Anne, Private capacity**

##### **KEYTE, Ms Robyn Joy, Private capacity**

##### **Developmental Disability WA**

HARVEY, Ms Taryn, Chief Executive Officer

##### **Disability Services Commission**

CHALMERS, Dr Ron, Director General

##### **Nulsen Disability Services**

CRABTREE, Mrs Jennifer, Manager, Service Development

TREWERN, Mr Gordon Douglas, Chief Executive Officer

WATT, Mrs Caroline Anne, Executive Director, Operations

WILLIAMS, Ms Sally Marina, Director, Health Services

**Goldfields, Individual and Family Support Association**

McBRIDE, Ms Kate, Service Operations Manager

NICHOLSON, Mr David John, Acting Chief Executive Officer

*Thursday, 19 February 2015*

*The Portside Centre, Sydney*

**Witnesses**

**National Disability Services**

ANGLEY, Ms Philippa, Executive Officer to the Chief Executive

BAKER, Dr Ken, Chief Executive

**First Peoples Disability Network**

AVERY, Mr Scott, Policy and Research Director

RIEMER, Ms June, Deputy Director

**Alzheimer's Australia**

BENNETT, Ms Carol, National Chief Executive Officer

SAMUEL, Mr Graeme, AC, President

SKLADZIEN, Dr Ellen, National General Manager, Policy and Programs

**Aged and Community Services Australia**

NEWMAN, Mrs Michelle, HACC Transition Program Manager

HALLIDAY, Mrs Illana Gaye, Chief Executive Officer, Aged and Community Services NSW and ACT

**Leading Age Services Australia**

CHADWICK, Mrs Natasha, Managing Director, Synovum Care Group

**Greystanes Disability Services**

LE BRETON, Mr John Vincent, Chief Executive Officer

**Royal Rehab**

GRAY, Mrs Delia, Executive Manager, Community Services

RYAN, Ms Natalie, Independent Living Coordinator

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**Young People in Nursing Homes National Alliance**

BLACKWOOD, Mr Alan McKenzie, Policy Director

MORKHAM, Dr Bronwyn Elizabeth, National Director

**WATSON, Ms Jane, Private capacity**

**EVERINGHAM, Ms Nicole, Private capacity**

**LOREN, Miss Mandi, Private capacity**

**BORK, Ms Jessica Ann, Private capacity**

**ABDO, Ms Jeanette, Private capacity**

**CROKER, Mr Bernard, Private capacity**

**CROKER, Mrs Christine, Private capacity**

**DRAPER, Professor Brian, University of New South Wales; and Euroa Centre,  
Prince of Wales Hospital**

**WITHALL, Dr Adrienne, Senior Lecturer, University of New South Wales**

**Summer Foundation**

BUTLER, Mrs Natalie, NDIS Connections Officer

FINIS, Ms Carolyn, Community Relations Manager

**BROWN, Mr Greg, Private capacity**

**IRVINE, Mr Jim, Private capacity**

**HICKEY, Mrs Keryn, Private capacity**

**JACOBS, Mrs Sharon Ann, Private capacity**

*Wednesday, 11 March 2015*

*Monash Conference Centre, Melbourne*

**Witnesses**

**MacKillop Family Services**

D'ELIA, Ms Mary, General Manager, Community Programs

FOX, Mr David, Director of Operations

**Melba Support Services Inc.**

FOARD, Mr Glenn Ian, Chief Executive Officer

ROSE, Mr Colin Leslie, Board Member

**Alfred Health**

O'SHEA, Mr William, General Counsel

PERTA, Mr Andrew, Clinical Services Director, Rehabilitation, Aged and  
Community Care

WAY, Associate Professor Andrew, Chief Executive Officer

**Catholic Social Services Victoria**

FITZGERALD, Mr Denis, Executive Director

**Wesley Mission**

DALRYMPLE, Mrs Marian Elizabeth, Manager, Wesley Neurological Support  
Services

**National Complex Needs Alliance**

CARTER, Associate Professor Christopher John, Member

MORGAIN, Ms Lyn, Chair

**Young People in Nursing Homes National Alliance**

BLACKWOOD, Mr Alan McKenzie, Policy Director

MORKHAM, Dr Bronwyn, National Director

**VEITCH, Mrs Wendy Joan, Private capacity**

**Children with Disability Australia**

BRIDIE, Ms Winnie, Information and Policy Support Officer

GOTLIB, Ms Stephanie, Chief Executive Officer

**BAJAY, Mr Pankaj, Private capacity**

**DE CRESCENZO, Mr Tony, Private Capacity**

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**DE CRESCENZO, Mrs Nancy, Private capacity****Multiple Sclerosis Limited**

FARRELL, Ms Deborah, Senior Manager, NDIS Futures

WALKER, Ms Sandra, General Manager, Service Innovation

**Huntington's Victoria**

GARDNER, Miss Tammy, Chief Executive Officer

**Huntington's WA**

JONES, Mrs Ann, Board Member and Immediate Past Chairperson

WALTER, Mrs Raelene, Executive Director

**Summer Foundation**

FINIS, Ms Carolyn, Community Relations Officer

WORSNOP, Mr Tom, Executive Manager

**BELLERT, Mrs Lauren Rae, Private Capacity****BLACK, Mr Daniel, Private Capacity****CLANCY, Mrs Bernadette, Private Capacity****JONES, Mr Ray, Private Capacity****JONES, Mrs Leona Faye, Private Capacity****NEWLAND, Mrs Ann, Private Capacity****PETERSEN, Ms Sam, Private Capacity****Victorian Coalition of ABI Service Providers Inc.**

TELFER, Ms Nicole, Executive Officer

WINKLER, Dr Di, CEO, Summer Foundation and Chairperson

**Freedom Housing Pty Ltd and Freedom Key Pty Ltd**

ILIOPOULOS, Mr Christos, Chief Executive Officer

*Thursday, 12 March 2015*

*Parliament of Tasmania, Hobart*

**Witnesses**

**Mt St Vincent Nursing Home and Therapy Centre Inc.**

KROMKAMP, Mrs Yvonne Silvia, Chief Executive Officer, Director of Nursing

**UnitingCare Tasmania**

O'NEILL, Ms Lindy Joy, Chief Executive Officer

PARKER, Reverend David Cameron, Chairperson

FITZGERALD, Mrs Lucia, Manager, Development Projects, Uniting Church in Australia, Synod of Victoria/Tasmania

**KinCare**

KNOX, Mrs Jennifer, State Manager, Tasmania

**L'Arche Australia**

TREANOR, Dr David, National Leader

TREANOR, Mrs Cindy, Community Leader

**Department of Health and Human Services**

CURTIS, Ms Annie, Area Manager (Southern Area Services), Disability and Community Services

GANLEY, Ms Ingrid, Director, Disability and Community Services

*Wednesday, 1 April 2015*

*Rydges Darwin Airport Resort, Darwin*

**Witnesses**

**Carpentaria Disability Services Incorporated**

McMAHON, Mr Gregory, Chief Executive Officer

**HPA Incorporated**

BURNS, Mr Tony, Chief Executive Officer

**Somerville Community Services Incorporated**

O'HALLORAN, Mrs Vicki, Chief Executive Officer

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**Darwin Community Legal Service, Aged and Disability Advocacy Service**

GIBBS, Ms Lorraine, Team Leader and Senior Advocate

**Multiple Sclerosis Society SA NT Incorporated**

SHAPLAND, Ms Susan, General Manager, Client Services

**MJD Foundation**

MASSEY BODILL, Ms Elizabeth (Libby), Director, Research and Community Services

**Step Out Community Access Service Incorporated**

SMITH, Mr Joseph, Manager

**Anyinginyi Health Aboriginal Corporation**

SANDERS, Mr Trevor, General Manager

**Department for Communities and Social Inclusion**

NOWAK, Ms Zofia, Director, NDIS Reform, Disability SA

WILLEY, Mr Paul, Director, South, Disability Services

CLIFT, Mrs Lucia, Acting Director, Community Services, Disability SA

*Friday, 15 May 2015*

*Parliament House, Canberra*

**Witnesses****The Salvation Army, Aged Care Plus**

BEWERT, Mr Peter, Executive Manager, Care Services

ROSENTHAL, Mrs Nicola, Business Development and Community Services Manager

**Hall & Prior Aged Care Organisation**

CAPLE, Ms Angela, Corporate Analyst

GRIEVE, Mrs Jennifer, General Manager, Health and Care Services

HITCHCOCK, Mr Daniel, Corporate Services Manager

PRIOR, Mr Graeme, Chief Executive Officer

**Families Australia**

BEDFORD, Ms Helen, Policy Officer

**Occupational Therapy Australia**

DOUGLAS, Ms Andrea, Clinical Adviser  
NORRIS, Ms Rachel, Chief Executive Officer

**Disability Advocacy Network Australia**

MALLETT, Ms Mary, Chief Executive Officer

**ACT Disability, Aged and Carer Advocacy Service**

DI MEZZA, Mrs Sonia, Deputy Chief Executive Officer  
MAY, Mrs Fiona, Chief Executive Officer  
ROSS, Mr Gordon Malcolm, Client

**Australian Bureau of Statistics**

MARQUARDT, Ms Michelle, Acting Assistant Statistician, Health and Disability Branch  
ZAGO, Mr David, Acting First Assistant Statistician, Social, Health and Labour Division

**Australian Institute of Health and Welfare**

BOLAND, Ms Justine, Acting Head, Community Services and Communication Group  
FLANAGAN, Ms Kerry, PSM, Director (CEO)  
SPYBY, Ms Kate, Senior Project Manager

**National Disability Insurance Agency**

BOWEN, Mr David, Chief Executive Officer  
CAIRNS, Ms Liz, General Manager, Operations Division

**Department of Social Services**

CHRISTIAN, Mr James, Group Manager  
de BURGH, Mr Russell Ian, Branch Manager, Policy Branch, Aged Care Policy and Reform Group, Ageing and Aged Care Services  
HARTLAND, Mr Nick, Group Manager  
PALMER, Mr Bryan, Group Manager  
WINKLER, Ms Deborah, Branch Manager, NDIS Governance and Stakeholder Relationships

**Department of Health**

ANDERSON, Ms Janet, First Assistant Secretary, Acute Care Division