

# **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.

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

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.

## **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**