

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 2006.¹ 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.

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.²

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 2005–06.³

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.⁴

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.'⁵

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 (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.⁶

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.⁷ 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.⁸

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'.⁹

5.11 Many submitters noted that the states and the Commonwealth should collaborate and 'work together to fund a new initiative' similar to YPIRAC.¹⁰ 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:

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.

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.¹¹

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.¹²

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.¹³

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'.¹⁴ In its 2012 report to COAG, the strategy outlines a series of reforms including the need to:

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 (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...¹⁵

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.¹⁶ 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'.¹⁷

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

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 (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.¹⁸

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.¹⁹

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)'.²⁰

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.²⁰

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

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...²¹

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'.²² Other submitters expressed concerns about how the 'bricks and mortar' will be funded.²³

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.²⁴

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.²⁵ 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

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.²⁶

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.²⁷

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.²⁸

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 2015.²⁹

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.

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, (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'.³⁰

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.³¹

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.

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.³²

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.³³

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.³⁴

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.³⁵

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

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 (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 (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 (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.³⁶

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.³⁷

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...³⁸

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.³⁹

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.⁴⁰

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.⁴¹

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

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.⁴²

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.⁴³ 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

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'.⁴⁴

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.⁴⁵ 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'.⁴⁶

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.⁴⁷ 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).⁴⁸ This can result in a young person being placed in a RACF without other options being considered.⁴⁹ Despite the presence of these pathways, it is still possible for individuals to fall between the cracks and risk inappropriate placement in a RACF.

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 (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 (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'.

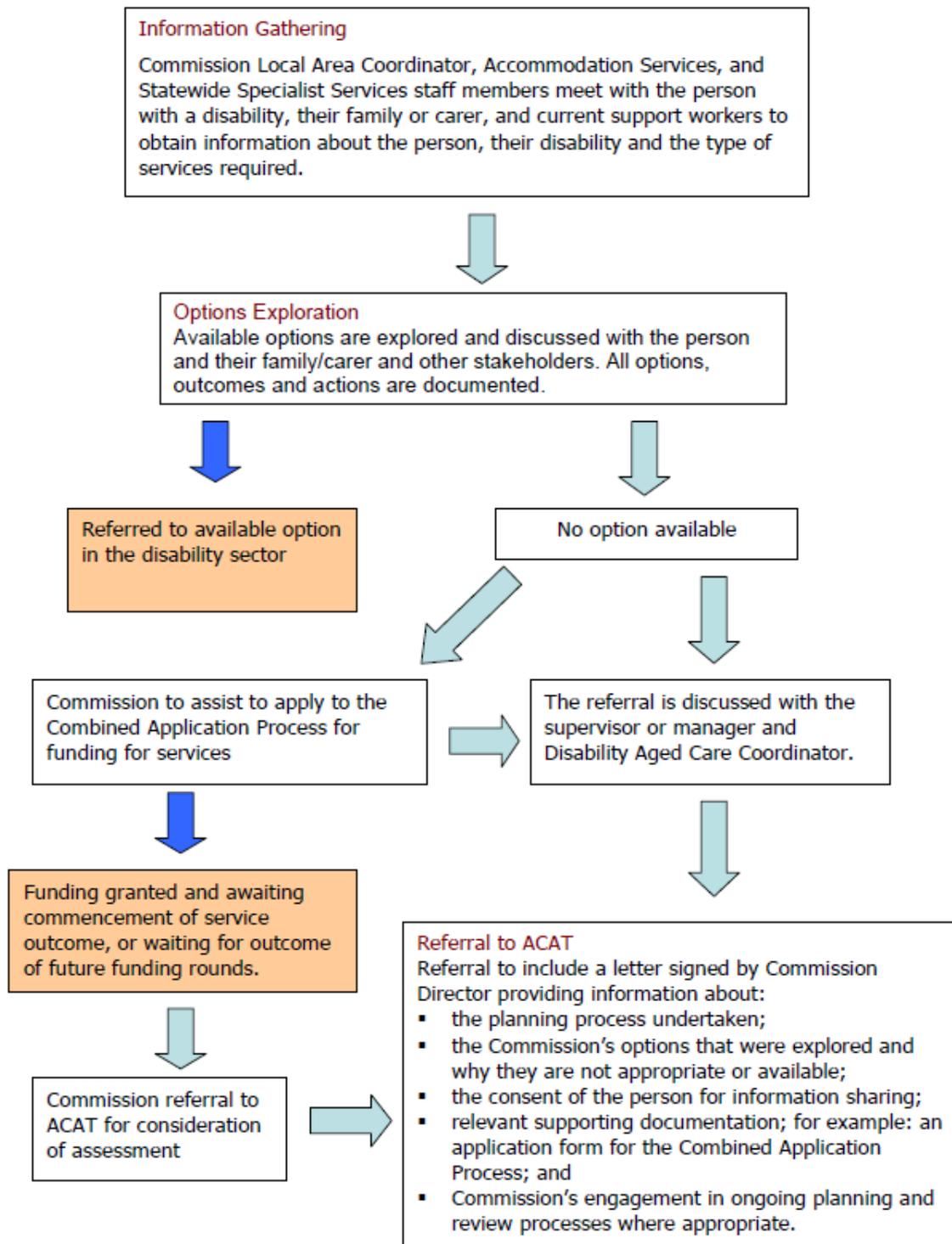
46 NSW Council for Intellectual Disability, *Submission 75*, p. 3.

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.

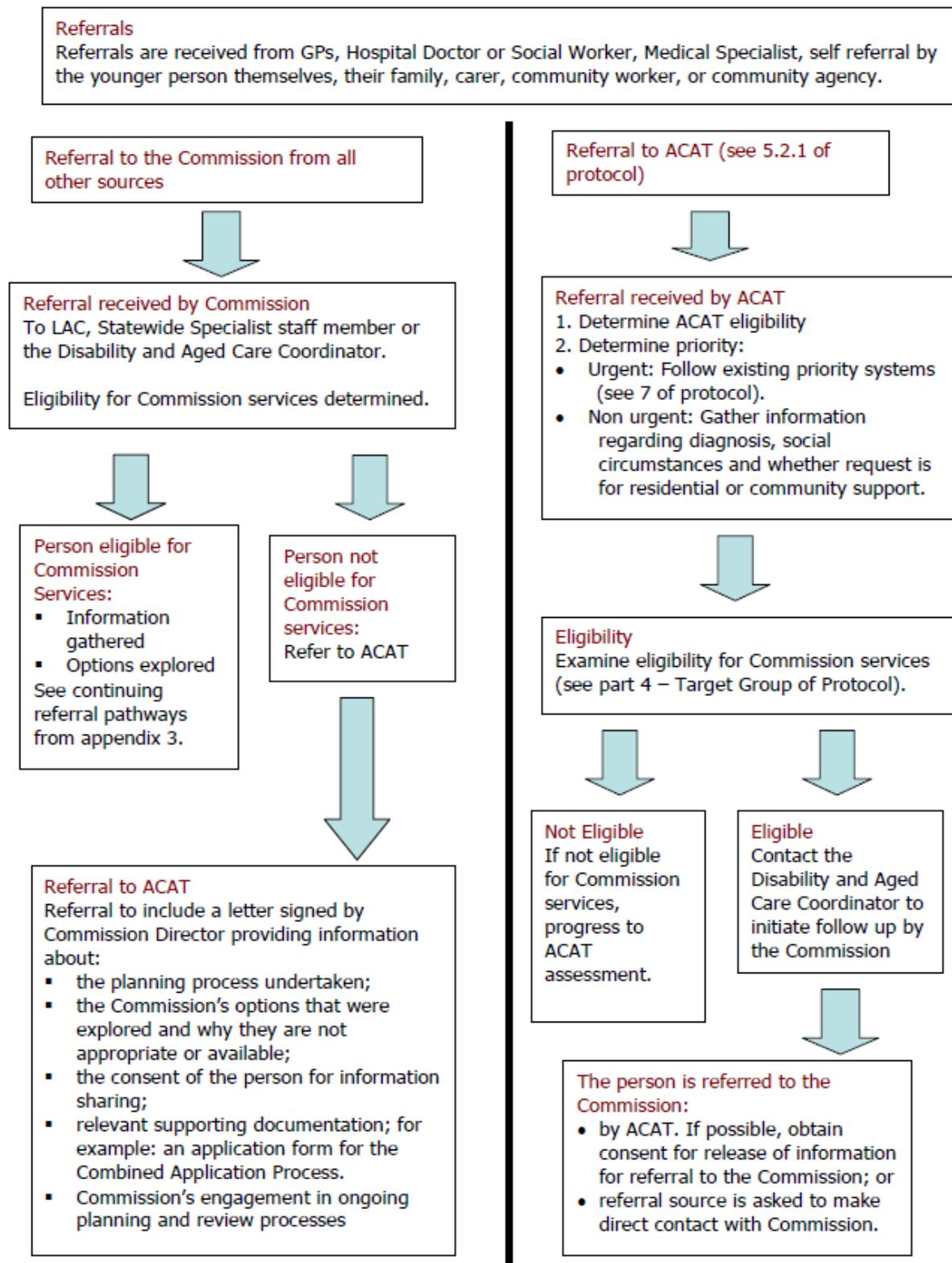
49 Brightwater Care Group, *Submission 115*, pp [15–27].

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.⁵⁰

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.⁵¹

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.⁵²

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

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 (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.⁵³

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.⁵⁴

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.⁵⁵

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

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.⁵⁶

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.

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.