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.[1] 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.[2]

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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'.[3]

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.[4] 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.[5]

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'.[6] 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.'[7] 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.[8]

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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.[9] 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…[10]

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.[11]

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.[12]

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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.[13]

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…
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> A local area coordinator employed by the Disability Services Commission regularly liaises with social workers in that hospital setting. [14]

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.[15]

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.[16]

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.[17]

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.[18]

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.[19]

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'.[20] 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).[21] 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.

approximately $70 000 per annum for an aged care bed.[22] 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.[23] 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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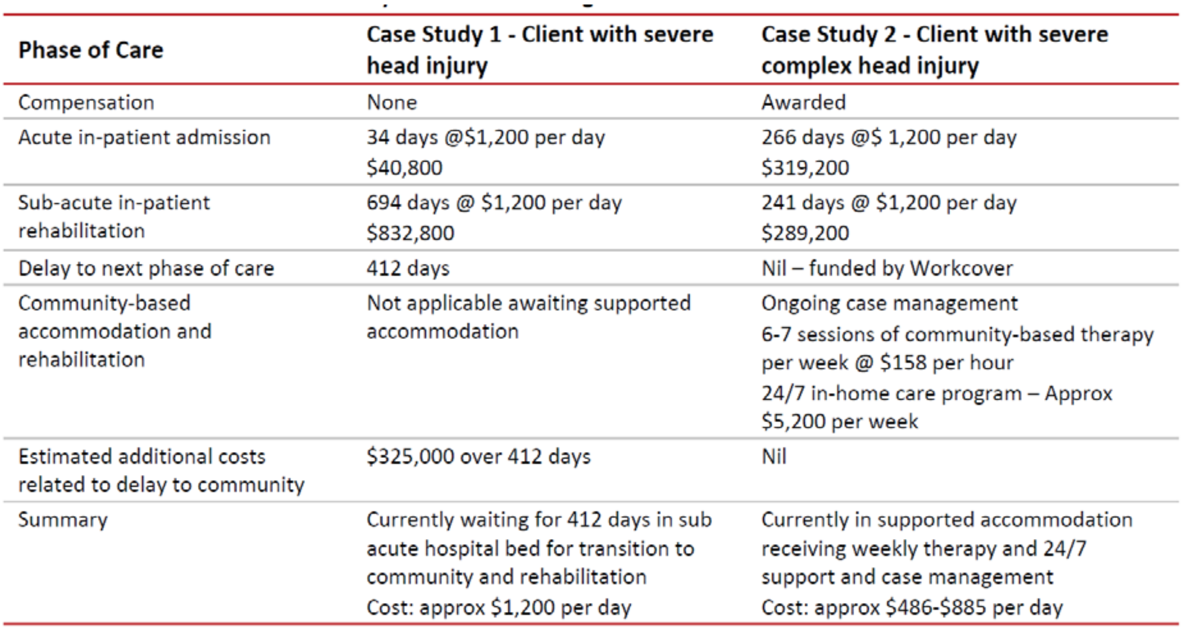
[22] See: Mr Russell de Burgh, Branch Manager, Policy and Evaluation Branch, *Committee Hansard*, Canberra, 15 May 2015, p. 41. Mr de Burgh told the committee that a facility can charge a basic daily fee of 85 per cent of the single rate of the aged pension or $47.49 per day. This contribution is on 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…
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> In WA, there are few hospital based rehabilitation and transitional services and even fewer non-hospital services such as provided by Brightwater Care Group.[24]

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'.[25] 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

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[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.[26]

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.[27]

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'.[28] 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.[29]

4.25 Mrs Helen Barker, mother of Angela, said that 'rehabilitation is the most important thing'[30] 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.[31] 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.[32]

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.[33] 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.[34]

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.[35]

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'[36]

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.[37]

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.[38]

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.[39] 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.[40] 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.[41]

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.[42]

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'.[43] 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/acat-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![44]

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.[45]

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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.[46]

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.[47]

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![48]

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.[49]

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.'[50] 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.[51]

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.[52] 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].

housing options for young people seeking to move from or avoid being placed in a RACF.[53]

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.[54] 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.[55] 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'.[56]

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.[57]

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:[58]

> **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.[59]

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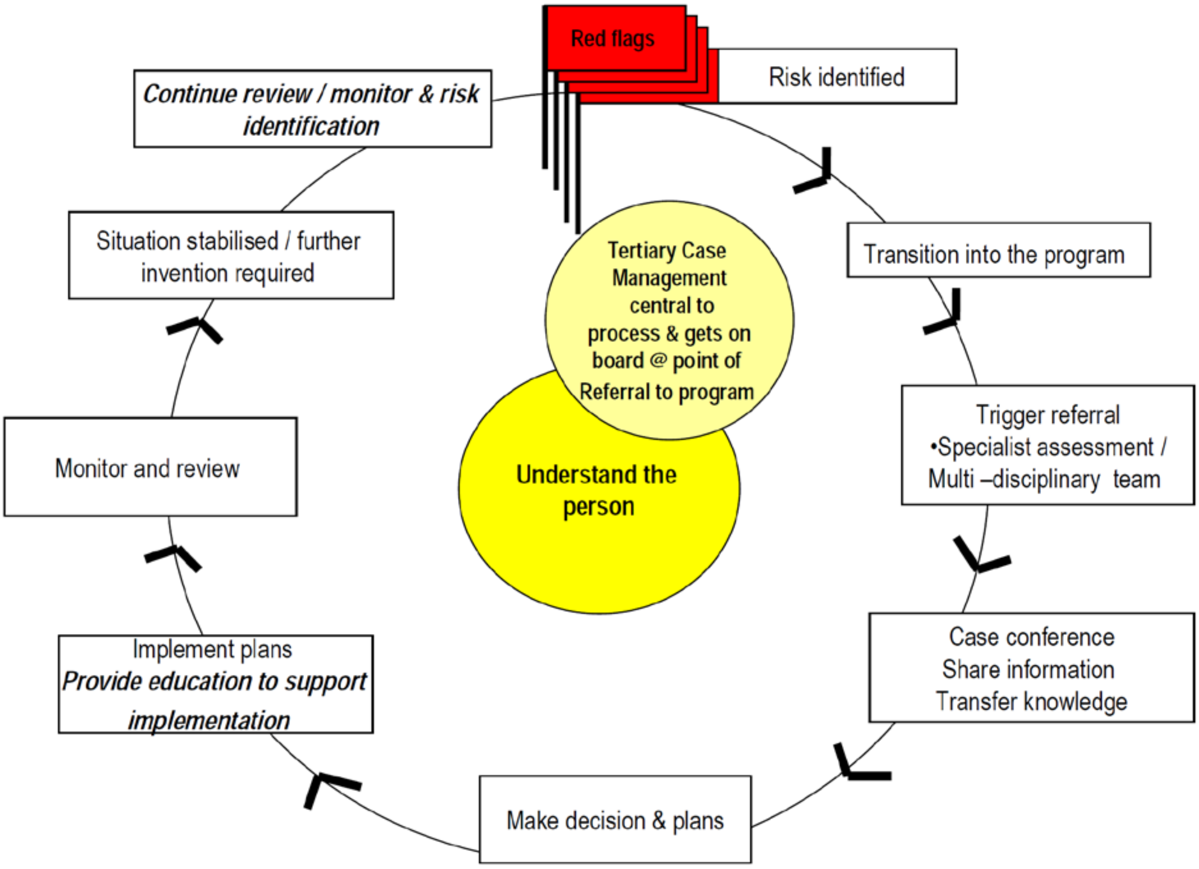
[57] Mrs Gail Palmer, Manager, Community Programs, Multiple Sclerosis Society WA, *Committee Hansard*, Perth, 17 February 2015, p. 13.

[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'.[60] 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

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[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.[61]

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:[62]

> 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.[63]

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[64]

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[65]; Melba Support Services[66]
Independent supported accommodation	Freedom Housing[67]
Intentional Communities	L'Arche[68]; Rowallan Park[69]
Supported accommodation	Royal Rehab[70]; HOPE Inc[71]
Hospital and Extended Care	Quadriplegic Centre
Residential Aged Care Facilities (targeted)	Mt St Vincent Home[72]

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

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[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 (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 (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*.

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.[73]

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.[74]

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.[75]

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.[76]

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.[77] 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.[78]

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'.[79] 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.[80]

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.[81]

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 (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.

> 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.[82]

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.[83]

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.[84]

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.[85]

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.[86]

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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.[87]

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.[88]

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'.[89] 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.[90]

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.[91]

Aboriginal and Torres Strait Islander peoples

4.79 Many Aboriginal and Torres Strait Islander peoples live in regional, rural or remote areas.[92] 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%).[93]

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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.[94] 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.[95]

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.'[96]

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.[97]

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.[98]

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.[99]

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.[100]

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'.[101] 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.[102]

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.[103]

4.90 Poor or non-existent advocacy can result in unintended consequences. Ms Sally Korbel 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.[104]

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.[105]

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.[106]

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…
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> 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 Korbel, *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.[107]

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.[108]

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.[109]

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

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'.[111] 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.[112]

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.[113]

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.[114]

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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.[115]

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'.[116] 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'.[117]

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.[118]

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.[119]

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.[120]

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.[121] 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'.[122]

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.[123]

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'.[124]

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.[125]

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.[126]

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'.[127] Other submitters noted that 'staff members are trained in aged care, but only a minority are also trained in the field of disability'.[128]

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'.[129] 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'.[130]

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.[131]

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.[132]

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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.

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.