Chapter 3

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

Introduction

3.1 This chapter discusses the following terms of reference:

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

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

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

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

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

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

International obligations

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

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

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

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

The right to choose a home

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

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

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

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

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

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

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

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

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

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

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

And a lack of involvement in basic tasks:

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

And inappropriate activities and poor community engagement:

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

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

Suitability of Residential Aged Care Facilities and other types of accommodation

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

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

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

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

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

> which resembled an unused storeroom being the last room at the end of a long corridor with excess equipment and furniture stored outside it. Her bedroom door was locked. We then returned to reception which was unattended to obtain a key. Halfway back up to the room we could not continue the journey. I found myself saying "I cannot put the key in the door, let's go home Ems" and we just left…
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> I just couldn't bear the thought of leaving my daughter in a place which felt so inappropriate. To me, it felt like I was just deserting her.[8]

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

Age appropriate accommodation

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

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

Further:

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

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

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

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

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

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

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

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

Access to services

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

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

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

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

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

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

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

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

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

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

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

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

> The only reason Daniel has a wheelchair is that the specialist who was looking after him was kind enough to pay for it, because I did not have the money after him being in hospital for a year…[17]
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> Our daughter has been given, by somebody who is very kind, a second-hand wheelchair. I was promised by the NDIS 12 months ago that she would have a purpose-built wheelchair. She is not going to live that long and I want that wheelchair really badly.[18]

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

Social inclusion and individualism

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

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

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

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

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

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

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

> You don't live in residential aged care, you just exist…
>
> It was the loss of freedom, loss of respect, loss of intelligence. Pretty much you were treated like a person needing aged care, that you haven't got a brain.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

> Manager but nothing was done. It was swept under the carpet like it normally is.[26]

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

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

Mental health

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

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

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

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

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

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

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

Aged care not young care

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

> [R]ecognises [that] aged care services are not designed for this cohort. The issues relate primarily to the lifestyle needs of younger people in relation to service choice, and here are many cultural, lifestyle and sexuality considerations around providing care for people in these circumstances, which Benatas is not well placed to provide.
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> For self-evident reasons, many of the services Benatas provides are age specific, and whilst adequate physical care may be able to be provided, lifestyle options and personal support suitable for younger people are not.[32]

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

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

The financial impost of living in aged care

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

> I pay 85% of my pension to the aged care facility. I’m not eligible for rent assistance because I live in a nursing home. I’m left with $50 per week for chemist bills including putting my medications in Webster packs, which is required by the facility. I have three Webster Packs made up each week and at a cost of $17 dollars just for the pack, the medication is an additional cost, so that's $51.00 per week gone already. I’m living in the red, I pay $45.00 per week on cigarettes, about $20.00 per week for my phone. I owe the chemist money, I owe the facility money and I owe Telstra money, it’s really stressful. Occasionally I buy a Tatts ticket on the off chance that I’ll win and get a little bit ahead…
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> Since my admission to [RACF], my ISP [Individualised Support Package] has been cut to $25,000 and they want to cut it to $6,000. I spend my

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

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

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

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

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

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

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

When is aged care suitable?

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

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

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

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

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

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

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

> There is this group, particularly younger males, often with alcohol related problems or other brain damage to the front part of the brain, where behaviours can get extremely challenging, and there are very few facilities across the country that can adequately provide quality care for these people…
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> [I]f you put people who are prone to behavioural disturbance in a unit where they are sitting…with no stimulation, no meaningful engagement, then yes, that will bring it on.[41]

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

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

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

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

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

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

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

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

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

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

Institutions and congregate care

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

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

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

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

Further, Ms Bruce noted:

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

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

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

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

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

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

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

> [D]espite the fact that many people with disabilities live there, some for most of their lives. Many people with disability in health facilities sleep in hospital beds in ward-type environments with other people. This is despite the fact that hospital beds are often not required for their disability (for example if they have an intellectual disability). It was submitted to the Public Advocate that the living conditions in one particular health facility:
>
> "directly contrasts how an ordinary home would look; dividing a multi-story building into living areas and providing sleeping arrangements where up to four people share a room is far from the ordinary home. Indeed, the centre is reminiscent of a nursing home which perpetuates the stereotype that people with a disability are sick and/or close to death." [47]

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

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

Further:

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

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

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

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

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

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

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

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

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

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

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

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

> Go to the dockyards (pub) and have a meal and then some drinks then on to cold rock for an ice cream or a milk shake…
>
> I am out most days, and often on Saturdays at mum and dad's place.[52]

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

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

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

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

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

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

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

> [E]ngage with and access their communities more frequently, at times developing friendships outside of the service delivery models; develop skills to use services and facilities within their communities, including undertaking personal shopping, banking and recreational and leisure interests and re-establish family connections and their roles as parent, partner, sibling and friend…
>
> Importantly there are options, designed to help them live the life they have chosen and the support to participate in the things that give them purpose.[54]

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

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

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

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

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

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

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

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

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

When Nicole and Craig Jones moved to Karroong:

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

For Craig, it was important that:

> He could bring his beloved dog Dusty with him…[58]

Respite—adequacy and access

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

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

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

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

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

> [F]amilies could certainly benefit from more respite. You cannot give too much. You can term that as 'early intervention' if you want…
>
> Coming back to the question of how you would do it better, for me it is: keep families together. If you build those resources and you give them those regular breaks—that is not me trying to get my service bigger—that respite can go right across. Everyone can be in that game, because it can be done in the community. I would much rather see it happen in the community than in a centre based facility.[59]

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

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

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

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

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

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

[61] Answer to Questions on Notice, Australian Bureau of Statistics, June 2015, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Additional_Documents, (accessed 4 June 2015). This equates to over 143 000 parent carers who have not accessed respite care.

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

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

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

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

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

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

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

Transition—crisis driven or planned

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

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

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

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

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

> meet the often complex health needs of young people with severe disabilities.[68]

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

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

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

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

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

Committee view

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

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

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

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

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

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

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

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