Submission to the Senate Inquiry regarding the adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia

Australian Psychological Society

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Executive Summary and Recommendations

This Inquiry is important, not only for those people aged under 65 living in residential aged care facilities (RACF), but also for the many other young (and not so young) Australians with severe disabilities with inadequate residential arrangements and care for their needs. This submission focusses on younger people in RACF specifically, but also makes reference to residential arrangements in general.

There is general agreement that existing residential care arrangements for young people with severe physical, mental or intellectual disabilities are inadequate. A key issue is the lack of residential care options available for young people with severe disabilities. Furthermore, the quality of residential care, when it does exist, is variable.

From a psychological perspective, the APS understands adequate residential arrangements to be those that promote good quality of life and wellbeing. As such, regardless of where a person lives, residents should be enabled to achieve emotional, physical and material wellbeing as well as having opportunities for age-appropriate interpersonal relations, personal development, self-determination, and social inclusion.

The term ‘young people’ is interpreted as people under the age of 65 years unless otherwise stated. It is noted that this represents an extremely broad group of people at different life stages with diverse experiences and needs. As such, it is likely that a range of solutions will be required. Conversely, while there are many discrete groups about whom this Inquiry relates, there are some key principles that underpin what all young people with disabilities need in relation to adequate residential care.

The findings of the latest Australian Government Productivity Commission Report on Government Services (SCRGSP, 2015) indicate that the existing system of disability support services is fragmented and underfunded, and provides assistance to just a quarter of people in need. These findings are supported by anecdotal reports from APS members, particularly in relation to gaps in the provision of specialised services addressing the health or mental health needs of people with severe disabilities.

‘Challenging behaviours’ have been identified as a barrier for many young people seeking suitable accommodation. Restrictive practices have often been used to ‘manage’ such behaviours. Moreover, inappropriately operated accommodation facilities can lead to or exacerbate challenging behaviours. Psychologists have particular expertise in the development and application of
non-restrictive practices and positive behaviour support programs, and thus have a potentially major role to play in reducing the need for restrictive practices and opening up support pathways for young people with complex needs.

Residential aged care facilities (RACF) are not designed for young people, and can have negative psychosocial impacts. Young people with disabilities have very different needs and requirements to their older counterparts. Aged care facilities are unlikely to have the resources to support the psychosocial and specific care needs of younger people with a severe disability.

More diverse and client-centred accommodation models are emerging, particularly in response to changes in the disability service system. However group homes are likely to remain central for those with severe intellectual disability.

While alternatives to RACF have been found, it is clear that considerable resources are required to meet the needs of residents regardless of the model. The primary considerations for finding suitable alternatives include:

- Ensuring adequate training levels and skill levels of care and rehabilitation staff
- Ensuring 24-hour care is available for residents
- Provision of individualised rehabilitation programs, equipment, and facilities
- Adequate connection with family, friends and the community (YPINH, 2010).

The NDIS will go some way to addressing these needs, and must accommodate any concerns arising from this Inquiry into its future rollout. However, adequate residential care arrangements cannot be the sole responsibility of the NDIS; rather, a collaborative effort with the aged care, health and housing sectors is vital.

Specifically, there is a need for more accessible and affordable housing options, and services that create pathways back to the community, such as slow stream rehabilitation. Not only is it possible to achieve transitions to more independent home-like accommodation, but it can ultimately lead to significant reductions in hours of support required.

If housing is affordable, suitable and secure, then it is likely that health will be optimised. Moreover, housing needs to be regarded as more than a human health need; it is crucial to recognise the importance of place and the potential of the built environment to facilitate positive and creative lives. Key
principles that may be utilised to guide future supported accommodation design relate not only to the built environment, but also the natural, symbolic and social environments.

**Recommendations:**

- The APS recommends better data collection, collation and reporting of the numbers of young people living in, or in need of, residential care, as well as future projections of likely support needs.
- The APS recommends that attention be paid to the learnings from the significant reduction across all states of the numbers of young people aged under 50 in permanent aged care following the five-year YPIRAC initiative.
- The APS recommends that attention also be paid to the implications of the projected increase in numbers of people with severe disabilities aged between 50-65 entering RACF, and their diverse support needs.
- The APS recommends action in three areas – improved awareness among people under 65 in aged care about their eligibility for the NDIS, prevention of new admissions to aged care through better pathways, and more affordable and accessible housing.
- Recognising that community support is a foundation for optimal care of all people with severe disabilities, the APS recommends that integrated and coordinated community and primary care services be the focus of initiatives to enable people to live in their preferred age-appropriate communities.
- The APS draws attention to the APS publication: *Evidence-based guidelines to reduce the need for restrictive practices in the disability sector*, along with a wide range of therapeutic and systemic responses designed and delivered by psychologists to reduce the impacts of disability and support optimal community or residential care arrangements.
- The APS recommends that policy initiatives focus on evidence-based interventions, particularly in the community sector, that support people with severe disabilities, their carers and families, in order to enhance quality of life and maximise their accommodation options within their local communities. This requires a greater recognition of the contribution of psychosocial experts such as psychologists and the importance of capacity building among carers and support networks in the community as well as in residential care.
Introduction

The Australian Psychological Society (APS) welcomes the opportunity to make a submission regarding the adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia.

While the issue is not new, it is hoped that the Inquiry will instill new energy and motivation for change, particularly by giving young people with disabilities and their families an opportunity to voice their concerns.

The UN Convention on the Rights of Persons with Disabilities (CRPD) states that all people with a disability have a right to live in the community. Unfortunately, there is a discrepancy between the aspirations of the convention and the lived experience of people with disabilities (Department of Families, Housing, Community Services and Indigenous Affairs, 2009).

This Inquiry is important, not only for those people aged under 65 living in residential aged care facilities (RACF), but also for the many other young (and not so young) Australians with severe disabilities with inadequate residential arrangements and care for their needs. This submission focusses on younger people in RACF specifically, but also makes reference to residential arrangements in general.

With the imminent rollout of the National Disability Insurance Scheme (NDIS), adequate residential care arrangements for young people with disabilities are as important as ever. Most importantly, providing adequate residential care is not just a task for the disability sector, but requires effective collaboration and pathways across a number of organisations and programs within aged care, health and housing.

From a psychological perspective, the APS understands adequate residential arrangements to be those that promote good quality of life and wellbeing. As such, regardless of where a person lives, residents should be enabled to achieve emotional, physical and material wellbeing as well as to have opportunities for age-appropriate interpersonal relations, personal development, self-determination, and social inclusion.

Responding to the Inquiry

The APS is not in a position to respond extensively to this Inquiry, but offers a brief response to each of the terms of reference below. The APS response draws on evidence-based psychological research and practice as much as
possible but is limited by what is available. The submission has also been informed by contributions from APS members working in the mental health and disability sectors in several states, most notably Western Australia and New South Wales.

Much of the content of this submission reports on the experience of young people with acquired brain injuries (ABI) – due mainly to the greater evidence base and associated funding received via the bodies such as the Victorian Transport and Accident Commission (TAC) and its interstate equivalents. Observations are also made where possible regarding the experiences of other groups (e.g., young people with intellectual disabilities and/or mental health issues).

**Definition of ‘young people’**
A primary focus of this Inquiry is on young people inappropriately living in residential aged care accommodation, and therefore the term ‘young people’ is interpreted as people under the age of 65 years unless otherwise stated. This is in alignment with current policy and research. As such, it is noted that this represents an extremely broad group of people at very different life stages with diverse experiences and needs.

**The Terms of Reference**

a. the estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care;

In 2005, it was estimated that 27,800 Australians with a disability under the age of 65 required accommodation support or respite services but were not receiving these services (AIHW, 2007).

In 2010 in Victoria, 1239 people with disabilities were reported to be in critical need of supported accommodation (Victorian Auditor-General’s Office; cited in Winkler et al., 2013). While the Supported Accommodation Innovation Fund at the time was expected to provide new accommodation for 53 people with disabilities in Victoria, this only provided a solution for 4% of those hoping to avoid RACF.

In 2013-2014, 7183 people aged under 65 years were living in RACF across Australia – 732 (10%) of these were under 50 (SCRGSP, 2015). It has been suggested that young people end up in RACF usually because there are no practical or viable alternatives (Strettles, Bush, Simpson & Gillet, 2005; cited in Winkler et al., 2013).
Taken together, these figures indicate that the number of young people living in RACF represents only a small fraction of the estimated numbers of people with disabilities in need of supported accommodation, and that an aged care facility is currently likely to be seen as a ‘least worst’ solution to those unmet needs.

**Recommendation:** The APS recommends better data collection, collation and reporting of the numbers of young people living in, or in need of, residential care, as well as future projections of likely support needs.

**b. short- and long-term trends in relation to the number of young people being cared for within the aged care system;**

At the end of the five-year Younger People with Disability in Residential Aged Care (YPIRAC) Initiative, there was a 35% decrease in the number of people under 50 in permanent aged care since 2005-6 (AIHW, 2012). This decrease in numbers has occurred across all States (SCRGSP, 2015).

However the numbers of young people (i.e., under 65) admitted to RACF across most States have increased across a similar timeframe (SCRGSP, 2015). But a single and significant drop (~35%) in the number of people under the age of 50 being admitted to RACF in Queensland has resulted in an overall reduction of 0.9% across Australia.

With the introduction of the National Disability Insurance Scheme (NDIS), preliminary data from the launch sites indicate that there will be an increase in the number of people under 65 in RACF (Winkler et al., 2013) (see Table 1). This is based on a prediction that 35% of people under 65 are likely to choose to remain in RACF with additional support services.

**Table 1. Projections of people under 65 in residential aged care**

<table>
<thead>
<tr>
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<th>Number of people under 65 in RACF</th>
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<tbody>
<tr>
<td></td>
<td>June 2012</td>
</tr>
<tr>
<td><strong>Hunter NDIS Launch Site</strong></td>
<td>128</td>
</tr>
<tr>
<td><strong>Barwon NDIS Launch Site</strong></td>
<td>81</td>
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<td><strong>ACT</strong></td>
<td>70-75</td>
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The Summer Foundation, an organisation established in 2006 to address the issue of young people living in nursing homes, reported that over 1500 young people with disability were living in aged care facilities across Victoria, with 139 aged under 50 (Summer Foundation, 2014). With no changes to the system, it is expected that an additional 70 people aged under 50 will
enter RACF each year in Victoria, and over 200 across Australia (Winkler et al., 2011).

In New South Wales, YPIRAC continues to accept applications for assistance for younger people with a disability living in or at risk of entering residential aged care, however there is a long waiting list for access to these services: [http://www.adhc.nsw.gov.au](http://www.adhc.nsw.gov.au).

While concerted efforts have been made to reduce the number of young people under 50 living in RACF, with some success, the ageing population is likely to mean increasing numbers of people with severe disabilities aged between 50-65 entering such facilities, and for some of this group who have always been cared for by their parents, or who are subject to premature ageing and dementia, aged care services might be the preferred option.

**Recommendation:** That attention be paid to the learnings from the significant reduction across all states of the numbers of young people aged under 50 in permanent aged care following the five-year YPIRAC initiative.

**Recommendation:** That attention also be paid to the implications of the projected increase in numbers of people with severe disabilities aged between 50-65 entering RACF, and their diverse support needs.

c. **The health and support pathways available to young people with complex needs;**

The findings of the latest Australian Government Productivity Commission Report on Government Services, *Services for People with Disability* (SCRGSP, 2015) indicate that the existing system of disability support services is fragmented and underfunded, and provides assistance to just a quarter of people in need. Nationally in 2012-13, the number of people with disability using specialist disability accommodation support services as a proportion of the estimated potential population was just 6.5 per cent.

The types of services offered to people with complex needs include day services, respite care, special education schools, family support, allied healthcare (e.g. speech pathologists, occupational therapists, psychologists), and medical professionals (GPs, psychiatrists) among others. Many services are especially costly for clients with complex needs. Individual support packages are available to assist with the costs and to attempt to better tailor support services on a case by case basis.

For people with an intellectual disability, supported accommodation is lacking, with international comparisons showing that the proportion of
government-funded residential services is much lower in Australia than in England and the USA (Stancliffe, 2002). This means that residential facilities are in high demand with long waiting lists, so there is little choice afforded to individuals and their families. Research to identify pathways to RACF reflects the greater reliance of people with intellectual disability on formal accommodation services at an earlier stage in the life cycle, which aligns with evidence to suggest that particular subgroups of people with intellectual disability (e.g. people with Down syndrome and cerebral palsy) are likely to experience premature ageing (Bigby et al., 2008). The most common pathway into aged care facilities for people with intellectual disabilities was from the family home. The main reason was due to death or ill health of the primary carer. This may highlight the inadequacy of community-based residential facilities, and/or of family support services for individuals with severe intellectual disabilities who live at home.

APS members working in the disability sector have provided the following information regarding the health and support pathways available to young people with complex needs in WA and NSW. There are many examples of individuals "falling through the gaps" due to the way in which services are funded, their eligibility criteria and coverage.

**Western Australia**
In Western Australia, there are no specialised treatment services addressing the health or mental health needs of people with intellectual disability. The WA Disability Services Commission (WADSC) has an intensive Positive Behaviour Support service for young people with severe challenging behaviours but anecdotal evidence suggests there is a lengthy wait list for this service.

Until the last 5 years or so, people in WA with intellectual disability under the age of 60 who developed dementia were not considered eligible for ACAT services. A memorandum of understanding was developed by WADSC with the appropriate service to recognise the earlier vulnerability of individuals with intellectual disability to dementia. As a result, ACAT will now assess an individual if there is a specialist diagnosis of dementia for someone with intellectual disability under the age of 60. However, if such a person is living in DSC-provided accommodation, the current policy for that person is to ‘age in place’. This means that residential aged care is the last resort when the person’s needs can no longer be met by DSC.

In WA there have been at least two major projects (early 1990s and a more recent initiative) aimed at moving young people with disability out of the aged care sector. These individuals typically had a brain injury acquired over the age of 18 years and not a developmental/intellectual disability. The
WADSC provides funding to service providers ‘cross disability’ (i.e. for people with disabilities other than intellectual), and funds and provides services (including accommodation) to people with intellectual disability and autism.

Many non-government service providers also provide accommodation which is generally targeted to the organisation’s area of expertise. For example, one service specifically caters for young people with ABI who require residential accommodation; another service is for people with Autism Spectrum Disorder; and yet another for people with cerebral palsy among others. People with psychiatric disorders technically remain the responsibility of State Mental Health Services under the WA Disability Services Act. However, people with intellectual disability are rarely accepted for treatment by Community Mental Health services. Some individuals with mental health issues and physical disabilities, including speech and communication difficulties, have not been accepted either. Our APS member informant reports that ‘not trained or experienced in the area’ is the usual explanation for rejection.

**New South Wales**

New South Wales has a few specialised services addressing the health or mental health needs of people with intellectual disability. One example is the Department of Developmental Disability Neuropsychiatry (3DN: [http://3dn.unsw.edu.au/](http://3dn.unsw.edu.au/)) which was established by the Chair of Intellectual Disability Mental Health in 2009. 3DN provides tertiary outpatient services, as well as e-learning for health professionals on intellectual disability health, and has recently published The Guide, a national framework of understanding and action for frontline mental health service providers for people with intellectual disability.

**Recommendation:** Recognising that community support is a foundation for optimal care of all people with severe disabilities, the APS recommends that integrated and coordinated community and primary care services be the focus of initiatives to enable people live in their preferred age-appropriate communities.

**Challenging Behaviour**

‘Challenging behaviours’ are commonly referred to in relation to people with disabilities, and have been identified as a barrier for many young people seeking suitable accommodation. For some, particularly those with Acquired Brain Injury (ABI) who may have cognitive and communication issues and are unable to clearly articulate their needs, their distress or frustration with their circumstances becomes manifested in challenging behaviours such as
screaming, swearing, throwing objects and hitting out. This can lead to the person being labelled 'difficult' and they can also become feared by other residents, visitors and sometimes staff (Commonwealth of Australia, 2005).

Anecdotal evidence indicates that residential facilities in the WA aged care sector are in high demand and providers can ‘pick and choose’ residents, with the least troublesome being given high priority. Thus, young people displaying challenging behaviours may find it particularly difficult to obtain accommodation. It is also the case that inappropriately operated accommodation facilities can lead to or exacerbate challenging behaviours.

Restrictive practices have often been used to ‘manage’ such behaviours. These practices include the use of restraint and seclusion as well as procedures and programs that can impede a person's ability to exercise choice and self-determination. Psychologists have particular expertise in the development and application of non-restrictive practices and positive behaviour support programs, and thus have a potentially major role to play in opening up support pathways for young people with complex needs.

A wide range of therapeutic and systemic responses have been designed and delivered by psychologists to reduce the impacts of disability and manage its co-existence with any health-related conditions. The APS (2012) was involved in developing a practice guide for psychologists on evidence-based psychological interventions that reduce the need for restrictive practices in the disability sector. These guidelines can be used in community and residential disability care settings and can be accessed from http://www.psychology.org.au/Assets/Files/Restrictive-Practices-Guidelines-for-Psychologists.pdf

Challenging behaviour is in part brought about by inadequate and inappropriate physical environments. "Challenging behaviour is mediated by a combination of interpersonal, organisational and environmental settings. Therefore, as well as careful assessment of interpersonal and organisational settings that clients are placed in, assessment of environmental factors is essential. The physical environment of an accommodation, respite, day support, educational or employment service influences both the behaviour of people with a disability and staff providing support. This may become a potential factor that influences decisions about the use of, or diminished need for, restraint or seclusion.” (APS, 2012, p.20)

Noise, overcrowding, service related factors, staff interaction style, and a lack of structured activities are all factors noted to potentially influence the incidence of aggression in persons with intellectual disability (Allen, 2000).
This highlights the need to be aware of the role of environmental factors on a person’s emotional state, and to employ a person-environment fit approach.

**Recommendation:** The APS draws attention to the APS publication: *Evidence-based guidelines to reduce the need for restrictive practices in the disability sector*, along with a wide range of therapeutic and systemic responses designed and delivered by psychologists to reduce the impacts of disability and support optimal community or residential care arrangements.

d. **the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities;**

There is substantial evidence to indicate that the existing aged care system in Australia does not adequately meet the needs of young people with disabilities. Nor is it always appropriate for aged persons to share their environment with younger people with different developmental needs.

Aged care facilities may not have the resources to support the psychosocial and specific care needs of younger people with a severe disability. Young people with disabilities have very different needs and requirements in comparison to their older counterparts. They may desire access to a range of alternative leisure pursuits and technology, as well as educational, employment and training opportunities, which reflect a variety of different developmental and life stages. A Victorian survey indicated that young people in residential aged care were at high risk of social exclusion, with 44% reporting to receive a visit from a friend less than once a year, and 34% never having had the opportunity to participate in community based activities (shopping, leisure, visits) (Winkler et al., 2006).

The Summer Foundation has shared numerous digital stories on its website ([www.summerfoundation.org.au](http://www.summerfoundation.org.au)) which document the experiences of young people in RACF. One such story was that of Michelle Newland who was placed in an RACF at the age of 19 after she acquired a brain injury from an asthma attack, as her parents had no other options. While in RACF, she states that she made very little progress, and medical advice indicated that she would not improve either physically or in her speech. The environment did not encourage or inspire her to live her life or try to get better, and she spent much of the time in bed. Through her own efforts she succeeded in being discharged just short of her 21st Birthday, and has defied medical advice and made huge steps in her recovery. She attributes her success in part to being able to return home, with the support of her family.
The Young People in Nursing Homes (YPINH) campaign predominantly targeted young people with acquired physical disabilities. However, there is a substantial proportion of ‘younger old’ people (i.e. aged between 60-80 years) with intellectual disability living in RACF whose experiences and needs have been less widely acknowledged (Bigby et al., 2008). Bigby et al. note that “concern about younger people with disabilities in aged care in Australia has led to a shift in Aged Care Assessment Service guidelines, which now require that all less restrictive options must be explored for a person under 65 years before residential aged care is considered. There have been reports that this new policy has led to refusals to assess ‘younger older’ people, which may, paradoxically, prevent older adults who experience premature ageing from receiving the services that are most appropriate” (p.406).

The Commonwealth Senate Standing Committee: Quality and equity in aged care (2005) also highlighted the potential risks of mixing people with severe disabilities with people with dementia, which can lead to assault, interference with medical apparatus or disruption to life support equipment.

These studies and anecdotal evidence highlight the importance of incorporating both developmentally appropriate and disability-specific considerations in the provision of accommodation and support services for people with serious and/or permanent mental or physical disabilities. In some cases, an aged care facility might be the appropriate solution for a prematurely ageing person; for younger persons who need to socialise with a peer group, or whose challenging behaviours are likely to be incompatible with an RACF environment, alternative systems of care and accompanying services are clearly needed.

**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;**

Since the 1970s group homes have been, and continue to be, a common model of providing services to people with intellectual disability in Australia (Bigby et al., 2014). Group homes are located within local communities and are staffed 24 hours a day by qualified support workers. The aim of this model of care is to support residents to live engaged, fulfilling lives within the community. Research has shown that staff practices within group homes as well as service culture and policy influence the quality of care provided.

While more diverse and client-centred accommodation models are emerging, particularly in response to the changes in the disability service system, group homes are likely to remain central to those with severe intellectual disability. In acknowledgment that group homes are here to stay, Bigby et al. (2014)
embarked on research to identify indicators of ‘good’ group homes. Using a quality of life framework, they identified the following domains:

- emotional wellbeing – resident wellbeing and satisfaction with life
- interpersonal relations – positive family relationships, breadth of social relationships, and being positively regarded by staff
- material wellbeing – a home adapted to needs, being able to afford the essentials, have own possessions, access to funds
- personal development – engaged and participating in meaningful activities and interactions
- physical wellbeing – good general health, access to health care, and a healthy lifestyle
- self-determination – autonomy, decision-making, and personalisation
- social inclusion – community presence and participation
- rights – dignity, respect, and privacy.

Importantly, in conceptualising good outcomes for this group, these domains have wider application to all systems of care available to people with complex disabilities.

The Summer Foundation provides information about an alternative housing model solution for young people with disabilities. Smart Homes, documented in detail on their website, are independent, fully accessible units, whereby residents have access to 24-hour care if required. It was hoped that the Supported Accommodation Innovation Fund could be used to develop this smaller scale and more family friendly accommodation and respite for up to 150 people with disabilities. It is certainly more appropriate for the 48% of people with acquired disability who have partners, and 27% who have school age children (Winkler et al., 2013).

While alternatives to RACF have been found, considerable resources are clearly required to meet the needs of residents regardless of the model. YPINH (2010) identified the primary criteria for suitable alternatives as:

- Ensuring adequate training levels and skill levels of care and rehabilitation staff
- Ensuring 24-hour care is available for residents
- Provision of individualised rehabilitation programs, equipment, and facilities
- Adequate connection with family, friends and the community (YPINH, 2010).

Ultimately, the YPINH Alliance (2014) argues that the key consideration in housing policy for Australians with a disability is the opportunity to make social connections.
f. the options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities;

De-institutionalisation of people previously considered unable to be accommodated in community settings has been enacted in different ways in different jurisdictions across Australia over the past 40 years but has not yet been fully realised nor consistently reviewed.

Western Australia DSC commenced a de-institutionalisation program in the late 1980s and now most residents with intellectual disability are accommodated in group homes scattered throughout the community. Most DSC hostels have been closed down. Organisations catering for people with physical disabilities mostly follow the small group home model, with some adopting a campus-type arrangement. WADSC influences the structure of these models via funding contracts.

The quality of care in group homes can vary significantly (Bigby et al., 2014). Research by Bigby and colleagues (2014) in Victorian group homes found that service cultures that viewed residents (not staff) as central and 'like us', and were open to change and new ideas, were factors common to better performing group homes. That service culture was found to impact on group home residents in various ways highlights the need to operationalise person-centred values and intentions.

A longitudinal study in Queensland examined the changes in behaviour and quality of life of 104 individuals who had moved to community-based group homes from long-term institutionalised care (Young & Ashman, 2004). Importantly, improvements were found in adaptive functioning and objective quality of life, and residents had greater opportunities for choice-making, indicative of a more active and normalised lifestyle. However, there were no changes in maladaptive behaviors – behaviours perceived by the researchers to be a consequence of living in an institution for such a long time. That these behaviours did not change was noted to have potential ramifications in residents’ new homes. Thus, while there were clear advantages for the individual residents in being de-institutionalised, there were some broader challenges for creating harmonious environments in the new group homes.

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;
In NSW, APS members report that all residents in group homes will be transferred across to non-government service providers as part of the transfer of all state government disability services under the NDIS.

Similarly, in Western Australia DSC is looking to reduce the number of residents with intellectual disability in its accommodation service by transferring many to the care of non-government organisations. This is in keeping with the current Government’s policies in the area.

In relation to mental health, the WA 10-year Mental Health Plan clearly states the intention to close down the major psychiatric hospital and move patients to community-based options. The WA Minister for Mental Health has been exploring the Italian Trieste model which provides 24-hour mental health services in local communities with a focus on prevention/early intervention. It is hoped that the recent Mental Health Plan will result in the development of more community-based options. There is also a working party currently developing models of mental health care for people with specific needs, for example, intellectual disability, people with Autism Spectrum Disorder and other neurodevelopmental disorders.

As in WA, the NSW Mental Health Commission’s 10-year Strategic Plan for Mental Health advocates closing the remaining stand-alone psychiatric institutions and shifting the focus of mental health care from hospitals to the community, which will hopefully increase the funding to community mental health (http://nswmentalhealthcommission.com.au/).

h. the impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation;

The NDIS is still in its infancy, and it is therefore too soon to assess its likely impact on the ability of young people in RACF to find more appropriate accommodation. Furthermore, as already presented in Table 1, the launch sites indicate that the numbers of young people in RACF are predicted to increase.

A recent report has outlined the costs that are likely be incurred by those wanting to remain in RACF as well as those wanting to move out (Winkler et al., 2013). Consequently, Winkler and colleagues conclude that the NDIS will be unable to meet needs and resources required for housing and support. Specifically, there is a need for more accessible and affordable housing options, and services that create pathways back to the community, such as slow stream rehabilitation.
In previous submissions, the APS has noted the great potential of the NDIS to be an effective national scheme that can address inequalities in the care of people with disabilities. However, recent research conducted jointly by the Centre for Disability Research and Policy and Young People in Nursing Homes National Alliance (2014) suggests that the NDIS must accommodate any concerns arising from this Inquiry into its future rollout. Their findings further highlight that it cannot be the sole responsibility of the NDIS, but a collaborative effort with the aged care, health and housing sectors.

**Recommendation:** In alignment with the work of Winkler and colleagues (2013), the APS recommends action in three areas – improved awareness among people under 65 in aged care about their eligibility for the NDIS, prevention of new admissions to aged care through better pathways, and more affordable and accessible housing.

i. **state and territory activity in regard to the effectiveness of the Council of Australian Governments’ Younger People in Residential Aged Care initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth’s contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction; and**

The five-year National Younger People in Residential Aged Care (YPIRAC) program assisted an estimated 250 people to move out of RACF and a further 244 people avoided being admitted (AIHW, 2012). Despite the improvement in the lives of those who have been helped by the program, an evaluation of the program by Winkler et al. (2011) concluded that it was unlikely to result in a long-term reduction in the number of young people in aged care. Specifically this was due to the lack of range and number of supported housing options, as well as the systemic change required to stem the flow of young people into RACF.

j. **any related matters.**

**Health, Housing and Place**

In a report on disability and inequality, VicHealth (2012) highlighted the known link between appropriate housing and health. If housing is affordable, suitable and secure, then it is likely that health will be optimised. The fact that people with disabilities are disadvantaged in the housing market makes them particularly vulnerable to the deleterious health effects of inappropriate accommodation.
Moreover, it is important to regard housing as more than a human health need, and recognise the potential of the built environment to facilitate positive and creative lives (Muenchberger et al., 2012). Place is a key determinant of psychological wellbeing, yet often provision of support is given precedence over the role of the built environment for people with disabilities. In their research investigating the experiences of young adults under 65 years with complex disabilities moving into purpose-built residential care, Muenchberger et al. identified some key principles that could be utilised to guide future supported accommodation design. These principles are restated below due to their pertinence to this Inquiry, and are categorised according to Kesler’s (2003) four components of a healing environment:

- **Built environment** - Safety and control over own environment, privacy for personal care (sight and sound), identifiable space transitions (moving through public and shared spaces to private spaces)
- **Natural environment** - Access to nature, views to nature, sensory experience, maximise natural light
- **Symbolic environment** - Sense of homeliness, ‘hidden’ disability design features, restorative spaces, identity promoting (personalisation), entranceways reflective of non-institutionalised facility
- **Social environment** - Multi-use spaces (to encourage relational interaction), gathering spaces, guest stay-over capacity (Muenchberger et al., p.2157).

**Slow stream rehabilitation and transitional services**

In their extensive and relevant work on the subject, one of the key recommendations made by Winkler and colleagues (2012) refers to the need for slow stream rehabilitation and transitional services to give people with severe brain injuries in acute hospitals the time they need to demonstrate their potential before they are forced into RACF. Furthermore, research by Sloan et al. (2012) with individuals with acquired brain injury concluded that not only is it possible to achieve transitions to more independent home-like accommodation, but that it can ultimately lead to significant reductions in hours of support required.

Similarly, Fisher et al. (2012) conducted research looking at the factors that determined discharge outcomes for inpatients with Huntington’s Disease. They found that patients discharged to residential care (as opposed to returning home) were more likely to have psychosocial and behavioural problems, and lengthy hospital stays – leading to an identified need for community-based psychosocial and behavioural management interventions which would prevent residential care admissions.
Working with clients with disabilities can require a prolonged intervention and relapse prevention phase to achieve outcomes. Psychologists are well placed to undertake behaviour management, pain management and injury adjustment, and also to address social participation, all of which can play a potentially vital role in rehabilitation post-injury and transition to appropriate community accommodation.

**Support for carers and families**
The experience of families of younger people with disabilities is physically, emotionally and financially challenging. Family members present with psychological stress and other issues including substance use disorders, eating disorders and depression. Carer depression and other psychological issues are particularly common in carers of people with younger onset dementia (Commonwealth of Australia, 2004). This indicates the need for a holistic service model which focuses on support for carers and family members as well as the individual with a disability.

**Recommendation:** The APS recommends that policy initiatives focus on evidence-based interventions, particularly in the community sector, that support people with severe disabilities, their carers and families, in order to enhance quality of life and maximise their accommodation options within their local communities. This requires a greater recognition of the contribution of psychosocial experts such as psychologists and the importance of capacity building among carers and support networks in the community as well as in residential care.

**Adequacy of residential aged care accommodation**
There is a wider issue around the adequacy of residential accommodation in general. If residential accommodation was more appropriate for ALL people, there would possibly be reduced issues for young people in particular.

In the words of one of our APS members (in relation to aged care),

> The major goal of the clinical geropsychologist in nursing homes should be to contribute to a fundamental change which would render the various institutions as authentic 'homes' in which residents could actualise their potentials for positive mental health, live with dignity, enhance their well-being, and live creatively.

(Pachana, InPsych, 2008, p. 495)

**Concluding Remarks**

There is general agreement that residential aged care is inappropriate for young people, and that it can have negative psychological impacts. However,
there are not enough residential care options available for young people with severe physical, mental or intellectual disabilities in Australia. Furthermore, the quality of residential care, when it does exist, is variable and it could potentially worsen under the NDIS. Of particular concern to the APS is the need for increased access to psychological interventions to minimise the use of chemical and other restraints.

There is good evidence about what is needed by young people with disabilities (regardless of group), and an overwhelming need for more appropriate housing options and a whole-of-government response. While there are many discrete groups about whom this Inquiry relates, there are some key principles that underpin what all young people with disabilities need in relation to adequate residential care.

Ultimately, this issue requires a creative and human response (Muenchberger et al., 2011) – “it’s about what it means to be human, as well as what it means to be housed” (Muenchberger et al., 2012, p.2157).

**About the Australian Psychological Society**

The APS is the premier professional association for psychologists in Australia, representing more than 21,000 members. Psychology is a discipline that systematically addresses the many facets of human experience and functioning at individual, family and societal levels. Psychology covers many highly specialised areas, but all psychologists share foundational training in human development and the constructs of healthy functioning. A key goal of the APS is to actively contribute psychological knowledge for the promotion and enhancement of community wellbeing.

Psychologists apply their skills and knowledge to enhance understandings of the individual, family and systemic issues that contribute to social problems, and to find better ways of addressing such problems. Psychology in the Public Interest is the section of the APS dedicated to the application and communication of psychological knowledge to enhance community wellbeing and promote equitable and just treatment of all segments of society.

The APS is well placed to contribute to this Inquiry by identifying psychological research and best practice relating to young people with severe physical, mental or intellectual disabilities. Recent APS engagement on issues relating to people with disabilities includes several submissions regarding the NDIS, as well as development of a practice guide aimed at reducing the need for restrictive practices in the disability sector.
Many psychologists work with people with disability in their everyday work across a range of settings including schools, hospitals and in private practice. Psychologists have much to offer people with disability, including the provision of interventions such as specialised assessment, mental health intervention, skills training, pain management, positive behaviour support, communication techniques, and environmental strategies. There is strong evidence supporting the benefits of psychological interventions in autism and intellectual disability, the two most prominent diagnoses amongst participants in the NDIS thus far. (Matthews, InPsych, 2014)

**APS submissions and resources relating to disability**


The development of the Practice Guide was the genesis for the establishment of an APS *Interest Group on People with Intellectual and Developmental Disability and Psychology*. The Interest Group was established to formally oversee the implementation of the Practice Guide and provide a national forum for promotion of psychological interventions to enhance the lives of people with disability. Morag Budiselik is the current Convenor of the Interest Group and more information can be gathered from the APS website ([www.groups.psychology.org.au/piddp/](http://www.groups.psychology.org.au/piddp/)).


*InPsych* articles


References


Department of Families Housing Community Services and Indigenous Affairs (2009). Shut out: The experiences of people with disabilities and their


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