
Young People With Disabilities Living In Residential Aged Care Facilities



‘the issue of young people with disabilities living in residential aged care facilities, is an issue that is a yet to be resolved’

This submission outlines the key aspects of the issue of young people with disabilities living in residential aged care facilities, how the YPIRAC program provided some real life changes for its participants.

- the unmet need is still huge,
- the work is just beginning.

Not only does **Australia need an individualised approach** for young people living in nursing homes, it also needs a broader systemic response that involves disability, housing, and health systems working in partnership.

The National Disability Strategy outlines a vision of general and disability services operating together to support and enable people with a disability to have genuine choice and control in their lives. The National Disability Insurance Scheme (*now called NDIA*) is a component of this strategy, but it **needs to operate in parallel with other initiatives** in order to realise this vision. The work is not yet done.

1. Executive Summary

In NSW, over 2000 people under 65 years live in residential aged care facilities today. These facilities are designed for people at the end stage of their life. They are no place for younger people with disabilities who are entitled to choice and control in how they live their lives. They are not equipped to provide rehabilitation, nor the kind of environment that maximises independence and social participation. They are designed and resourced for end-of-life care for older people.

This issue is urgent, and there are no current funded government plans to adequately address it.

These 2000 people under 65 years who live in residential aged care facilities in NSW have very little opportunity for a permanent and appropriate home that enables them choice and control over their lives. Further, hundreds more face the prospect of entry into an aged care facility as there are no other accommodation options available that suit their needs.

The issue is well acknowledged and was addressed by Government from 2006 - 2011. Significant data from the 1990s and early 2000s indicated the extent of the issue, and led to the establishment of the national YPIRAC program, a collaborative national – state/territory approach worth \$244m per annum (\$122m from the Commonwealth, matched by \$122m from the states and territories).

This program was largely successful, and resulted in significant improvements in independence and quality of life for the individuals who received a service. Rehousing some 121 individuals. However, it was just a start, and only met a fraction of the demand. The program finished in June 2011, and there are still no plans for a funded government strategy with the same aims to continue the important work.

There is no funded strategy in Australia right now to address the issue.

Applications are still being taken for the YPIRAC program, but there are no further funds, and successful applicants are placed on a needs register for an indefinite period. Applicants in the Hunter region are being referred to the National Disability Insurance Scheme agency—NDIA. **There is an expectation the National Disability Insurance Scheme will fix the problem, but it won't.**

We welcome the launch of the NDIA. This will go a long way to addressing significant social and support needs of people with disabilities in Australia. However, it is not resourced nor designed to provide bricks and mortar accommodation that people with 24 hour support needs require. Further, it is not resourced nor designed to provide the long term specialised clinical needs that these people require to enable their choice and control.

Further, there is promise in the establishment of a National Injury Insurance Scheme (NIIS), as this includes strategies around infrastructure development, including supported housing and services, and funds for rehabilitation. BIA NSW is keen to see the NIIS developed as soon as possible, although we note this Provider was refunded in 2012/14.

This is not a 'disability-specific' issue. It needs a whole-of-government systemic approach. Every evaluation report from the YPIRAC program, and every piece of literature discussing this issue states it requires a partnership approach from Health, Housing, Aged Care, and Disability departments. It is neither realistic nor practical for it to be the sole domain of the Disability services.

This issue is symptomatic of a broader systemic service provision issue. Young people with high level nursing care needs have no place in the disability service system. Addressing this issue will not only provide opportunities for improvements in dignity, independence and meaning to these young people, but will also address systemic problems in disability, health, and aged care systems.

These people are legally and ethically entitled to accommodation and supports that maximise their choice and control. We urgently need a longer term funded strategy (and, in the meantime, an immediate interim solution).

These people have waited long enough. The waiting lists are growing. The few that have benefited from YPIRAC stand as a stark contrast to those still waiting. There are no new funds to assist people to move out into the community.

Mrs BARBARA PERRY (Auburn) [4.36 p.m.]:

Clearly young people should not be living in residential aged care facilities, but unfortunately that is where many people with brain injuries—people with high-end needs—are placed.

Hansard

Australia has Human Rights obligations to its citizens.

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), to which Australia and its states and territories is a party, articulates the right of persons with disability to live independently and to be included in the community. This is now formally recognised by the Australian Government. The NDIS Act 2013 states that, amongst other things, its objects are to “in conjunction with other laws, give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006”.¹

However, NDIA cannot do this alone, and other service systems, operated within the states and territories, must also work to fulfil these obligations.

French and colleagues explain: “Article 19 requires parties to recognise the equal right of all persons with disability to live in the community, and participate in community life, with choices equal to others. It also requires parties to ensure the full enjoyment of this right by taking effective and appropriate measures that will ensure that persons with disability:

- Have the opportunity to choose their place of residence and where and with whom they shall live on an equal basis with others;
- Are not obliged to live in a particular living environment;
- Have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community.”

Further, as Article 19 is a civil and political right, it must be immediately complied with.²

2. Why are RACFs inappropriate for younger people?

BIA NSW has no criticism of the work of staff in Residential Aged Care Facilities (RACFs) in relation to their younger residents. The point we make is that the setting and environment is not designed nor resourced to meet the needs of younger people with disabilities, and further, cannot provide the environment required to enable people’s choice and control.

YPINH Alliance 2004: It is now well understood and acknowledged by governments, policy makers, the aged care sector, the health sector, and the disability sector, not to mention families, communities, and residents themselves.

The Young People In Nursing Homes Alliance cited the following in its 2004 submission to the Senate Inquiry on aged care, articulating what is now well understood and acknowledged by governments, policy makers, the aged care sector, the health sector, and the disability sector, not to mention families, communities, and residents themselves:

- “Because aged care facilities are not designed to cater for the very different and more intensive needs of younger people and are certainly not funded to provide for these needs, facilities and staff struggle to provide the care these young people require. ...

¹ National Disability Insurance Scheme Act 2013 (Cth), Para,3 (1)(a)

² French, p25

- Staff do not have the requisite skills and knowledge to care for younger people with Acquired Brain Injuries. Nor are they trained to deal with the specific care needs of other disabilities, such as Multiple Sclerosis, Muscular Dystrophy or Parkinson's disease.
- Aged Care Nursing Homes have a clear lack of rehabilitation orientation.
- The resources needed to purchase appropriate equipment to support the complex care needs of young people do not exist.
- Therapeutic input is required to maintain an individual's physical, cognitive and social functioning. The resources to manage this input are largely unavailable. So too are the resources needed to foster that individual's rehabilitative potential.
- Aged Care Staffing levels are insufficient to maintain and promote independence.
- ... ● Thousands of frail older Australians are unable to access the aged care places they need because younger people are taking up these places."³

In the Victorian context, the Summer Foundation conducted an evaluation of the changes in people's quality of life as a result of the YPIRAC program. Importantly, they noted that the significant improvements that occurred as a result of people's participation in YPIRAC (to be outlined later in this submission):

"[had come] from a very low base where many participants in aged care led lives impoverished in the extreme. Prior to the receipt of supports through the initiative, participants did not have the opportunity to make the everyday choices that most of us take for granted. They were effectively excluded from community life. They also had limited access to adaptive equipment. One man spent two years without a communication device which, once supplied through an enhancement package, now enables him to express his thoughts and needs. Others were unable to sit out of bed comfortably because prior to the initiative they did not have a suitable wheelchair with customised seating."⁴

3. Who are the younger people living in Residential Aged Care Facilities?

This is a population of people with an enormously diverse range of experience, needs, and wishes. There are people with a variety of acquired disabilities sustained through catastrophic injuries or events such as stroke. There is also a significant group who live with degenerative neurological diseases such as Multiple Sclerosis, Muscular Dystrophy or Parkinson's Disease, and who require an episodic approach to nursing care.

We now have a diverse population, often with few needs in common, and from widely varying age groups.

The Young People in Nursing Homes Alliance explains: "Over the last 50 and more years, advances in medical technology and improved health care have delivered growing numbers of individuals with significant acquired disability and a range of clinical and other needs that are beyond the support capacity of the existing disability system. Their need for clinical interventions and sometimes, specialist nursing levels of care, means that in the absence of a system wide capacity to respond, nursing homes have been the default 'answer' for these young people".

³ National Alliance of Young People in Nursing Homes (2004), pp3-4

⁴ Summer Foundation, p3

The Alliance goes on to say that this default 'answer' is not an answer at all, as it does not offer the 24 hour nursing care that it has been widely assumed it does. This was recognised by the Senate Inquiry into Quality and Equity in Aged Care in 2005.⁵

...this means is that these people are living in an environment that, in most cases, can meet neither their social participation requirements, nor their clinical and rehabilitative needs.

4. The Young People In Nursing Homes (YPIRAC) Initiative

YPIRAC was the first truly national effort to directly address this issue. An initiative of the Commonwealth of Australian Governments (COAG) in February 2006, in response to the previous year's Senate Inquiry, YPIRAC directed \$244m in federal and state / territory money over five years to the aim of reducing the net number of people under 65 years living in RACFs by between 425-689 people.

There were three objectives:

- 1.** Move younger people with disability currently in residential aged care into appropriate supported disability accommodation; where supported disability accommodation can be made available and only if the client chooses to move;
- 2.** Divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation; and
- 3.** Enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care, and if residential aged care remains the only available suitable supported accommodation option.

State and territory governments were responsible for the implementation of YPIRAC, and in NSW, this was undertaken by NSW Government Department of Families and Community Services – Ageing, Disability and Home Care (ADHC).

The target group covered people with disabilities living:

- in aged care facilities - both hostels and nursing homes;
- in acute care facilities who cannot return home and whose only option is placement in an aged care facility; and
- at home with aging carers, at risk of admission to aged care facilities⁶

The Australian Government provided \$122 million for the implementation of the YPIRAC Program over five years. The State and Territory Governments matched funding provided by the Australian Government, creating a total Program funding pool of \$244 million over five-years.

⁵ Young People in Nursing Homes National Alliance (2011), p7

⁶ Australian Government (FaHCSIA), p1

Funding was allocated based on the number to be targeted, and the activities to be undertaken in each jurisdiction. The table below provides a summary of the Australian Government funding commitment to each jurisdiction ⁷

Table: Australian Government five-year funding allocations - YPIRAC

NSW	Vic	SA	Qld	WA	Tas	NT	ACT
\$40,638,871	\$30,126,251	\$9,202,265	\$23,866,328	\$12,108,871	\$2,900,649	\$1,215,057	\$1,941,708

The Australian Institute of Health and Welfare (AIHW) was commissioned to develop a national data set (NMDS) and collection process relating to the program.

5. YPIRAC: Implementation and results

The program was implemented in different ways in each state and territory.

In NSW, the following process was followed. Initial priority was given to people aged under 50 years. ADHC wrote to all residents of residential aged care facilities aged under 50 years to tell them about the program and how to apply. ADHC then accepted applications, and assessed them for eligibility for an assessment. Successful applicants were allocated a Support Planner, who then assessed them for eligibility to receive services. Support Planners would then work with eligible people to assess the services required and oversee the service. NGO providers were contracted to provide services, and Enable NSW was contracted and funded to provide equipment for 50 participants. This approach differed from that taken in some other states and territories, where the assessment process was outsourced to NGO providers.

How many people accessed the program?

The Australian Institute of Health and Welfare published a report ⁸ in April 2012 outlining, among other things, the number of people who had received a service for the five years of the YPIRAC program.

Nationally:

Over the five years of YPIRAC from 2006-07 to 2010-11:

a) an estimated 1,432 people received services from the YPIRAC initiative.

Of these:

- an estimated 250 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation);
- 244 people achieved the second YPIRAC objective (diversion from residential aged care); and
- 456 people achieved the third YPIRAC objective (receiving enhanced services within residential aged care, when this was the only available, suitable accommodation option).

⁷ Australian Government (FaHCSIA), p7

⁸ AIHW (2012)

b) The total number of permanent residents of residential aged care aged under 65 has generally decreased and, in particular, there was a **35% drop in the number of persons under 50** living in permanent aged care between 2005–06 and 2010-11.⁹

c) The total number of people under 50 years assessed by ACAT as needing long-term high level residential care (a proxy measure to enumerate the number of people at risk of entering RAC) fell by 20% and the number recommending low level care in residential aged care fell by 21%. During this time the total number of ACAT assessments for people aged under 50 increased by 9%.¹⁰

YPIRAC in NSW:

The NSW Government launched the YPIRAC initiative in 2007. The State invested \$40.1 million in the program to match the \$40.1 million from the Commonwealth.

There are two published reports outlining the outcomes of YPIRAC in NSW, each completed at a different time, so the results in each vary. BIA NSW understands that YPIRAC activity has continued subsequent to both these reports, so current figures are likely to be different again. A major reason cited by ADHC for the delay in people achieving outcomes under YPIRAC is the lack of actual accommodation, and considerable time and YPIRAC resources have gone into planning and then constructing bricks and mortar. Therefore, people who have been approved for a place outside of an RACF have been moving out as buildings are completed, and this is still ongoing.

A summary of the figures from each report is cited here.

The AIHW report (April 2012) documented information regarding the five years of the initiative until 30 June 2011.

According to AIHW, in NSW over the five years of YPIRAC from 2006-07 to 2010-11:

a) an estimated 307¹¹ people received services from the YPIRAC initiative.

Of these:

- an estimated 55 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation);
- 14 people achieved the second YPIRAC objective (diversion from residential aged care); and
- 177 people achieved the third YPIRAC objective (receiving enhanced services within residential aged care, when this was the only available, suitable accommodation option).

⁹ AIHW (2012), p4

¹⁰ AIHW (2012), p9

¹¹ AIHW (2012), p.34. Note: Regarding these figures, AIHW states they are “a running total over 5 years of the YPIRAC initiative. Numbers may not add to the total number of YPIRAC users as not all service users may have achieved objectives, and some service users may have achieved more than one objective as their circumstances or service availability changed over time.”

b) There was a 27% drop in the number of persons under 50 living in permanent aged care between 2005–06 and 2010–11.

The other published report is the evaluation of the NSW YPIRAC initiative, conducted by Health Outcomes International¹², which was completed in May 2011, and contained projections for some of the outcomes (i.e. What was planned and expected to be achieved by 30 June 2011).

According to this report:

a) 268 people were approved for the YPIRAC initiative.

Of these:

- 48 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation), with a further 73 awaiting the “completion of YPIRAC funded facilities”, expected to be completed by March 2012¹³ ;
- 113 people achieved the second YPIRAC objective (diversion from residential aged care through provision of appropriate supports¹⁴); and
- 471 ‘packages’ were provided to an unspecified number of people in relation to the third YPIRAC objective (receiving enhanced services within residential aged care, when this was the only available, suitable accommodation option). According to the report, these packages comprised “in-reach packages, equipment, case management and home modifications”. The report notes that additional packages may be provided beyond this number as required¹⁵.

There is quite some discrepancy between the two reports in the measurement of the second objective. BIA NSW suspects this is because this is the most complex of the three objectives to measure.

6. Outcomes of the YPIRAC program

At only the half way point, YPIRAC’s mid-term review concluded that

“there is a body of quantitative and qualitative data to support the conclusion that the Program is having a very positive impact on young people with disabilities who either reside in, or are at risk of entering, residential aged care”.¹⁶

In Victoria, the Summer Foundation compiled an evaluation of the Quality of Life outcomes of the YPIRAC program in that state. It concluded that the majority of service users who received services under YPIRAC, as well as their families, demonstrated improvements in quality of life [bearing in mind the comments noted earlier in this report about the baseline being very low]. 68 participants were interviewed, including 34 people who had moved out of residential aged care, 11 people who were provided with services to keep them out of aged care, and 28 people who received enhancements within the aged care setting.

¹³ NSW Government (ADHC) (2011), pp37-38

¹⁴ NSW Government (ADHC) (2011), p39

¹⁵ NSW Government (ADHC) (2011), p42

¹⁶ Australian Government (FaHCSIA), p22

The report states:

“For the RAC Exit Group [the group moved out of aged care], the initiative has demonstrated that not only can people with high disability support needs be successfully supported to live in community settings, but that also their lives are enriched when placed in more normalised, age-appropriate environments with person-centred supports. The RAC Exit Group had more frequent community access and was provided with more opportunities to make everyday choices. There was also an increase in its frequency of social contact. Group members spent fewer hours in bed, and went outside more often. A more home-like environment and additional supports enabled some people who moved to demonstrate their potential for increasing their independence in a range of personal and domestic tasks.”¹⁷

In relation to the those who were diverted from entry into aged care, the report found that people were able to

“harness informal supports and resume existing or modified life roles that younger people who had been living in RAC for many years did not”¹⁸.

The evaluation of the NSW YPIRAC program found similar, very positive results from its interviews with people who had received services from the YPIRAC program. It reported:

“The young person with a disability and their families participating in the YPIRAC program were on the whole very positive with relation to their priority needs being met and the subsequent improvements to their quality of life.”¹⁹

The evaluation report found that the direct support provided for people as having “a significant positive impact on their quality of life” included:

- Speech and communication training
- Building mobility and physical strength
- Enhancing social connectedness and personal confidence
- Home modifications
- Supply of equipment
- More appropriate accommodation options.

Individuals and families reported enormous benefits from having physical health needs met. Direct services that, until YPIRAC, were simply not available in the residential aged care setting, were highly valued and appreciated: services including speech therapy, physiotherapy, and occupational therapy.

The evaluation report describes, through case studies, interview reports, and direct quotes, the significant positive outcomes people experienced, including improved speech (through therapy), improved mobility and independence (through therapy, equipment supply and home modification), and improved social connectedness (through therapy, age appropriate accommodation, logistical and transportation supports).²⁰

¹⁷ Summer Foundation, p2

¹⁸ Summer Foundation, p2

¹⁹ NSW Government (ADHC) (2011), p4

²⁰ NSW Government (ADHC) (2011), p4

BIA NSW is of the opinion that access to these services is a fundamental human right, and the YPIRAC program made possible a service that these people should have been receiving for years.

Impact on RACF admissions and permanent resident numbers.

During the 5 years of the YPIRAC program, there was a marked decrease in the number of people aged under 50 years living in RACFs, as well as the number of admissions for this age group. However, there was a 3% increase in residents aged 50-64 years.

Table 1: Number of permanent aged care residents aged under 65, by age group, Australia and NSW, as at 30 June, 2006 to 2011; and percentage change in population from 2006

	Australia			NSW		
	Under 50 years	50 -64 years	Total	Under 50 years	50 -64 years	Total
2006	1,007	5,550	6,557	391	1,952	2,343
2007	945	5,632	6,557	374	1,997	2,371
2008	857	5,752	6,609	335	2,036	2,371
2009	810	5,693	6,503	333	1,989	2,322
2010	715	5,763	6,478	304	2,059	2,363
2011	658	5,723	6,381	287	2,010	2,297
%	-34.7%	3.1%	-2.7%	-26.6%	3%	-2.0%

*Source AIHW 2012, p7

The charts that follow present this information graphically.

Many... ‘young Australians with a disability require services from several areas of the human services system at the same time but rarely get them as the systems don’t work together, cross sector collaboration will not only deliver the integrated services young Australians with disability need, but will help the NDIS deliver on its social and economic objectives.’

Dr Bronwyn Morkham

Chart 1: Number of permanent aged care residents aged under 65 in Australia, by age group, as at 30 June, 2006 to 2011

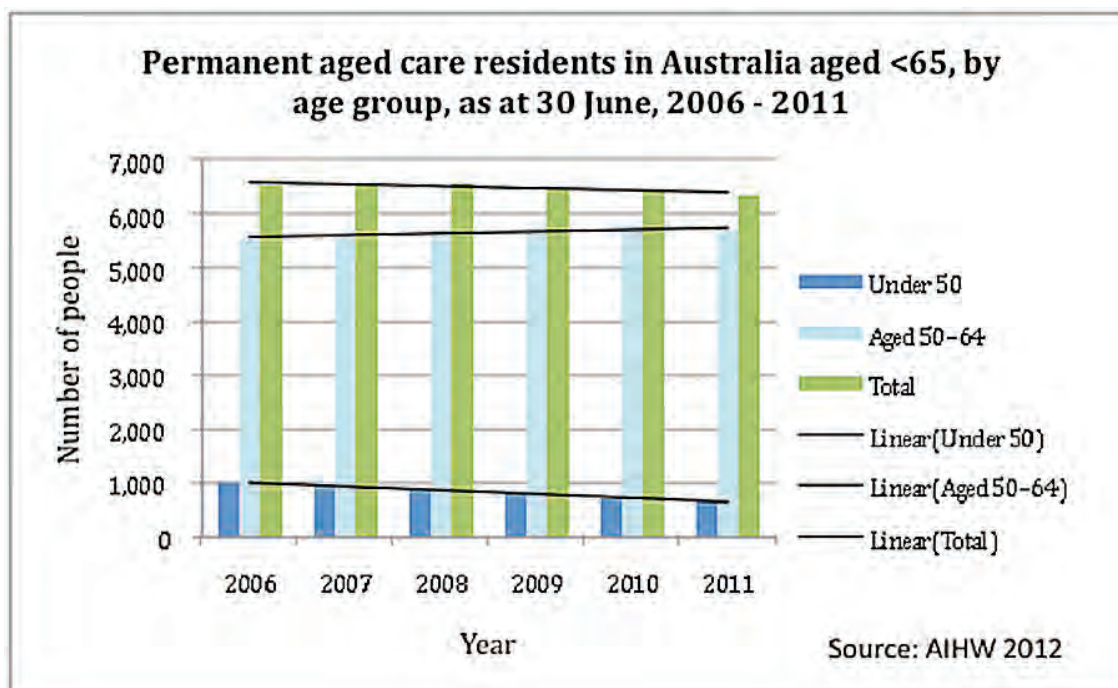
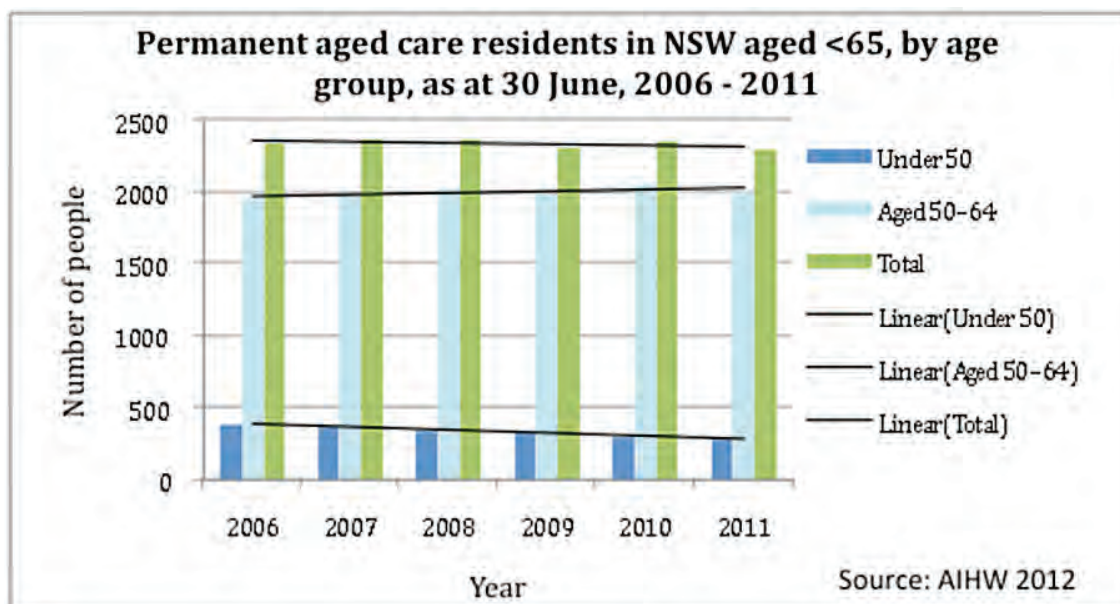


Chart 2: Number of permanent aged care residents aged under 65 in NSW, by age group, as at 30 June, 2006 to 2011
Number of admissions to RACF.



The number of people aged under 50 years being admitted to RACFs has reduced during the 5 years of YPIRAC by 37% in NSW and 35% in Australia. However, there was an increase in admissions for those aged 50-64 years.

Table 2: Number of people admitted to permanent residential aged care aged under 65, by age group, Australia and NSW, 2004–05 to 2010–11

	Australia			NSW		
	Under 50 years	50 -64 years	Total	Under 50 years	50 -64 years	Total
2004 - 05	318	1,700	2,018	117	577	694
2005 - 06	262	1,662	1,924	89	587	676
2006 -07	234	1,602	1,836	90	573	863
2007 -08	208	1,648	1,856	76	568	644
2008 - 09	232	1,667	1,899	93	578	671
2009 - 10	204	1,708	1912	68	591	659
2010 - 11	207	1,733	1,940	74	598	672
% Change	34.9%	1.9%	3.9%	36.8%	3.6%	3.2%

*Source AIHW 2012

This information is presented graphically on the following page:

“Supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services. ”

Chart 3: Number of people admitted to permanent Residential Aged Care in Australia, aged under 65 years, by age group, by year, 2004-05 to 2010-11.

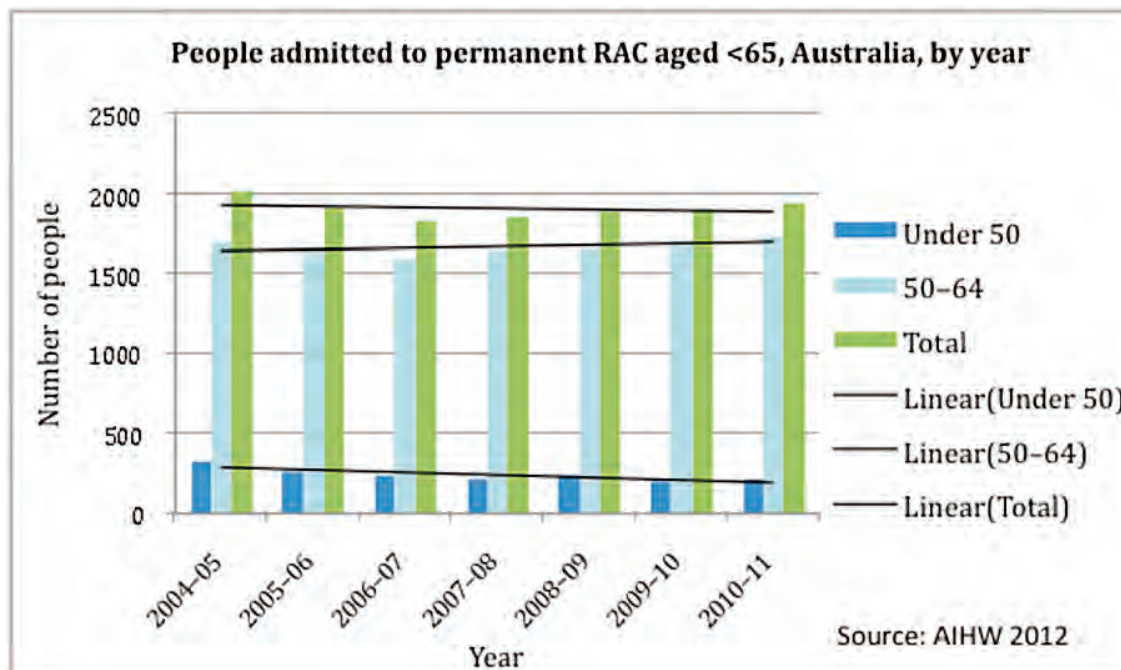
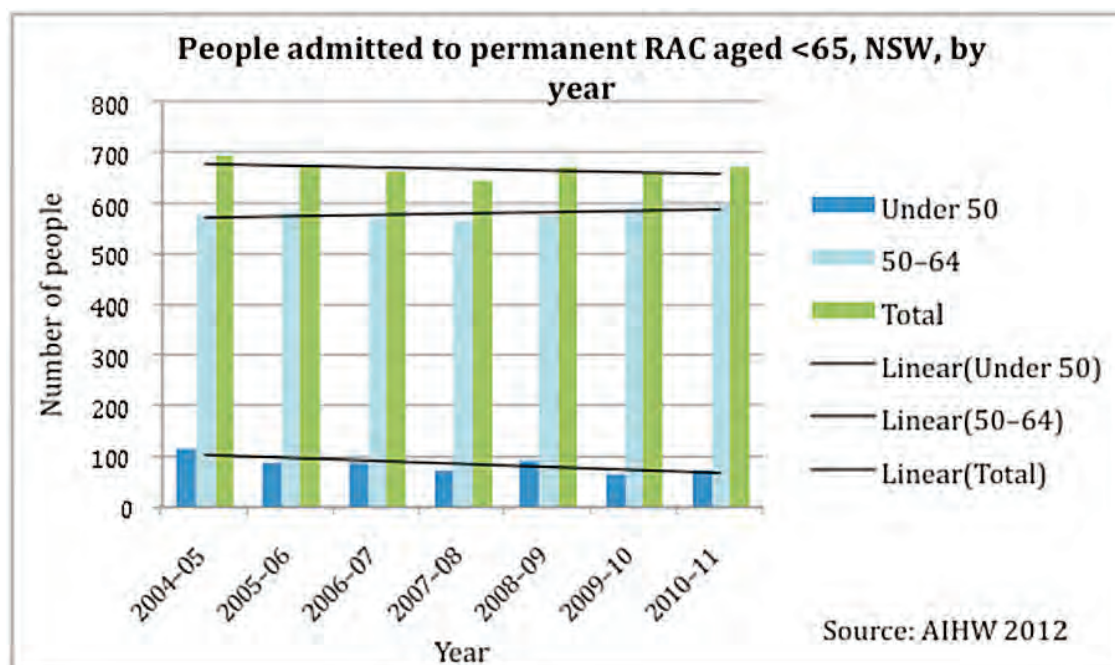


Chart 4: Number of people admitted to permanent Residential Aged Care in NSW, aged under 65 years, by age group, by year, 2004-05 to 2010-11.



Data on admissions and permanent RACF population since July 2011 is not yet available, so we are as yet unable to comment on the impact on these, if any, of the YPIRAC program ceasing.

7. YPIRAC is only the beginning: Continuing needs and lessons learnt

“While the Program will make a positive contribution to this previously neglected group, many young people in residential aged care will continue to have significant needs that cannot be met within current funding allocations.”²¹

“There is a need for the program to continue, and expand, to address unmet demand. This is evidenced by the program’s inability to effectively address the cohort of people outside the initial target group.”²²

“Despite the numbers of people that needed YPIRAC assistance greatly overwhelming the program’s capacity to deliver to no more than 10% of the YPINH cohort, there is no question that the demand for targeted assistance is present and growing.”²³

The above quotes, from three different sources, support the need for an ongoing program or range of strategies that directly target this particular group of people. They also support the idea that it is not a complex solution that is needed. These people simply need appropriate supports to enable them to live where they choose: a roof over their head, therapeutic services, and individualised support with daily activities.

In 2012, the National Young People in Nursing Homes National Alliance prepared a report for FaHCSIA with ‘lessons learned’ from YPIRAC, and recommendations for the next phase, which it named ‘YPIRAC2’.

The Alliance argued that YPIRAC had established some solid foundations for future development, and although it had achieved some good outcomes, it represented only the beginning of an ongoing Government priority. The report articulated the “complexity of need and the YPINH cohort’s lifelong need for multiple service area involvement”, and recommended “YPIRAC2” be founded on strong formal links between disability services health, aged care, and housing.²⁴

Focus on systemic reform is needed.

The most positive outcomes of the YPIRAC program have been at the individual and family level, with some small improvements in system capacity (e.g. through development of some new accommodation).

However, the lessons learnt from YPIRAC also extend to the broader systems level, with a key priority emerging out of the evaluation for a systemic approach to provision of supports. The Mid Term Report states: “Supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services.”²⁵

²¹ Australian Government (FaHCSIA), p23

²² NSW Government (ADHC), p14

²³ Young People in Nursing Homes National Alliance (2011), p28

²⁴ Young People in Nursing Homes National Alliance (2012)

²⁵ Australian Government (FaHCSIA), p5

This remains a challenge for governments, and the design of NDIA has not taken this lesson on board.

Australia has a challenge for the next 4 years before the NDIA is fully rolled out to develop and build these relationships – incorporating health and housing services into the design of NDIA in Australia.

Further, the Young People in Nursing Homes National Alliance states that the YPIRAC program demonstrated that it is significantly more expensive and complex to move a person out of an aged care facility than it is to provide the services to prevent them having to enter one in the first place.²⁶ It noted that each state and territory exceeded their targets for 'diversion' through appropriate targeting of resources to enable people to remain in the community. It is hoped that this is something that NDIA will be able to continue. The problem in Australia is that it won't be rolled out in all areas until 2018.

8. A brief step back in time. Why did YPIRAC start?

YPIRAC was born following a Senate Inquiry conducted in 2004-05, which itself emerged from a National Summit (held in May 2002) to explore the extent of the issue of the lack of appropriate supported housing options for younger people with disabilities requiring 24 hour support. The Summit was the first national event to bring attention to the issue, and concluded with a Call for Action to the federal government.

The Senate Inquiry was detailed and wide-ranging, and presented compelling evidence that was immediately met with a response from the Coalition of Australian Governments (COAG) announcing the establishment of YPIRAC.

The Senate Inquiry recommended, among other things:

"Recommendation 22, 4.167 The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most instances. The Committee therefore recommends that all jurisdictions work cooperatively to:

- assess the suitability of the location of each young person currently living in aged care facilities;
- provide alternative accommodation for young people who are currently accommodated in aged care facilities; and
- ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options."²⁷

In the Government's response in September 2007, the YPIRAC program was announced and articulated. It had begun in 2006, as COAG had been aware of the Senate Committee's recommendations, reflecting the Government's acknowledgement of the importance and urgency of the issue.²⁸

This was urgent in 2002. 11 years later it is still urgent.

²⁶ Young People in Nursing Homes National Alliance (2012), p.29

²⁷ The Senate Community Affairs References Committee (2005)

²⁸ Some 10 years earlier, in 1995, the then NSW Ageing and Disability Department (now ADHC) conducted a national research project into the prevalence of younger people living in residential aged care facilities, and compiled recommendations for alternatives. Data were collected from 811 RACFs across Australia (55% of all RACFs), and 1515 residents aged under 60 years were surveyed. Information was also collected from 76 former residents, also aged under 60 years. The project found that in NSW, 3.8% of residents were aged under 60 years (cf 4.0% nationally). Despite the survey indicating that these residents required additional supports relating to their disability, 61% did not receive any 'special or additional support services'. [ADD p28]. The survey concluded that as only 3% of younger people had been successful in obtaining more appropriate accommodation, sustainable solutions were required. [NSW Government (ADD) (1995)]

The Summit concluded that the development of a sustainable way forward depended on two crucial advances. The first was the urgent need for a national no fault insurance scheme to cover catastrophic injuries and the onset of degenerative disease. The second was the need for the development of a range of accommodation and support options, with federal and state governments jointly responsible for their requisite funding needs.²⁹

Australia has finally achieved the first, but has a long way to go on the second.

9. Current Status

On 1 January 2009, the Commonwealth State and Territory Disability Agreement (CSTDA) was replaced by the National Disability Agreement (NDA), which provides the framework for the provision of government support for people with disability. Australian Government funding for the YPIRAC initiative was rolled into funding provided to the state and territory governments for the NDA.³⁰

The DSS website states: "The YPIRAC initiative was incorporated into the National Disability Agreement when it came into effect in January 2009. At the October 2011 meeting of the Standing Council on Community, Housing and Disability Services, Ministers agreed to a continued effort to meet each of the objectives under the YPIRAC initiative and agreed to achieving better connections with mainstream services for younger people with disability in, or at risk of entering, residential aged care."³¹

Presumably, this commitment continues, and the Ministers still wish to see the needs of this cohort of people directly addressed through Government action. However, it is not flowing through to actually meeting the needs of the YPIRAC target group.

Current status in NSW.

In NSW, applications are still being accepted for the YPIRAC program, but all YPIRAC funds have been fully committed, and no further funding is available for new applicants. Applications may be assessed, but are then placed on a needs register, and there is no guarantee the applicant will ever receive a service. There are no current plans in NSW to fund this program.

Applicants who fall within the boundaries of the National Disability Insurance Scheme launch site are referred to DisabilityCare Australia for consideration. However, as will be discussed below, that agency can only offer a limited response to these people's needs.

It would appear the expectation is that as DisabilityCare Australia rolls out to other parts of NSW, people within the YPIRAC target group will be assessed for support under its regulations and operational guidelines.

²⁹ Young People in Nursing Homes National Alliance (2011), p8

³⁰ AIHW (2012), p.5

³¹ From the FaHCSIA website accessed 5/8/13
[www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative]

Health Outcomes International states:

“Even taking into account that a residential aged care facility [RACF] is the preferred option for a certain number of clients, the number of people under 65 years of age residing in Aged Care [in NSW] who could be assisted by the YPIRAC program is likely to be in excess of 2000 people. Given the YPIRAC program has assisted 268 people to date, this represents a very small proportion of the potential demand. As noted earlier, in order to cope with this demand, it was considered necessary to target those people already residing permanently in a RACF and aged less than 50 years of age as a priority.

This leaves two cohorts that have yet to be effectively targeted [in NSW]:

- Young people with a disability residing in a RACF between the ages of 50 and 64, and
- Those people not currently residing in a RACF but at risk of entry into a RACF.³²

There appears to be an assumption by the NSW Government and the community that the NDIA will effectively target these people. However, for the reasons outlined below, it will not.

DisabilityCare Australia – the National Disability Insurance Scheme.

It appears to be widely expected that NDIA will deliver solutions for the deficiencies within the disability systems throughout Australia. There is no doubt it will go a long way towards addressing many of them. However, its current design and guidelines do not allow for an effective systemic response to the issue of younger people with disabilities living in residential aged care.

BIA NSW is not suggesting that NDIA should fund these things.

What we are saying is that proper formal relationships must be built between NDIA and other service systems (most notably Housing NSW and NSW Ministry of Health). ***This is a social and economic imperative for the NSW Government.***

Further, this needs to occur at both the individual participant level and at the broader systemic level, with policy development and implementation from both NDIA and the other service systems working together.

NDIA will not fund accommodation

The National Disability Insurance Scheme Rules 2013 state:

“Schedule 1 sets out matters for the CEO to have regard to in considering whether supports are most appropriately funded or provided through the NDIS, rather than through other service systems”^{33,34}.

³³ National Disability Insurance Scheme (Supports for Participants) Rules 2013 (as made on 18 June 2013), Para. 3.5.

³⁴ ‘Service systems’ as defined the Rules are: “general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered: (a) as part of a universal service obligation; or (b) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.” National Disability Insurance Scheme (Supports for Participants) Rules 2013 (as made on 18 June 2013), Paragraph 6.4

The relevant excerpt from Schedule 1 reads:

Housing and community infrastructure

7.19 The NDIS will be responsible for:

- (a) supports to assist a person with disability to live independently in the community, including by building their capacity to maintain a tenancy, and support for appropriate behaviour management; and
- (b) home modifications for accessibility for a person in private dwellings; and
- (c) home modifications for accessibility for a person in legacy public and community housing dwellings on a case-by-case basis but not to the extent that it would compromise the responsibility of housing authorities to develop, maintain and refurbish stock that meets the needs of people with disability; and
- (d) user costs of capital in some situations where a person requires an integrated housing and support model and the cost of the accommodation component exceeds a reasonable contribution from individuals.

7.20 The NDIS will not be responsible for:

- (a) the provision of accommodation for people in need of housing assistance, including routine tenancy support and ensuring that appropriate and accessible housing is provided for people with disability; or
- (b) ensuring that new publicly-funded housing stock, where the site allows, incorporates Liveable Housing Design features; or
- (c) homelessness-specific services including homelessness prevention and outreach, or access to temporary or long term housing for participants who are homeless or at risk of homelessness; or
- (d) the improvement of community infrastructure, ie accessibility of the built and natural environment, where this is managed through other planning and regulatory systems and through building modifications and reasonable adjustment where required.

In other words, NDIA will not, in the vast majority of cases, fund the building of accommodation.

In its evaluation of the YPIRAC program in NSW, Health Outcomes International noted:

Four key factors influence a person's assessment of what they consider "appropriate" accommodation. ... Through the consultation four factors consistently came through as influencing a person's assessment of the appropriateness of accommodation.

- Level of care – given the often complex physical health needs of the young person, the availability of quality care that could be provided was the most common and critical influencing factor.
- Proximity to family home – this is driven by a desire to provide as 'normal' existence as possible and was an important factor for family who more often than not visited their loved one daily and adopted a relatively involved caring role.
- Proximity to relevant community facilities – young people and their families expressed a desire to be accommodated close to community facilities, or places of interest to the young person. Access to entertainment, sports, theatre events or being near the beach/river etc. was identified as important factors.
- Personal desire for independence – understandably each young person has their own level of desire for independence, influenced by their capacity to manage independently. Some are naturally sociable and enjoy the companionship provided through shared accommodation, whereas others strongly desire a more independent lifestyle, though still seeking close links to family, friends and community."³⁵

³⁵ NSW Government (ADHC) (2011), p.9

Health Outcomes International identified Housing as a significant partner missing from the implementation of the YPIRAC program in NSW, and as a consequence, NSW experienced significant delays and costs in its efforts to move people out of aged care.³⁶

If as a society we are to achieve the aims of the National Disability Strategy and meet the obligations under the UN Convention for Persons with a Disability, the above factors are crucial. NDIA, however, cannot deliver on the above without effective partnerships with providers of housing, most notably Housing NSW, and look to maximise the effectiveness of pooling resources to support people to live where they choose to live.

This is a whole-of-government issue, not just one for Disability services.

DisabilityCare will not fund the necessary therapies these people need to maximise their independence, choice and control.

There is considerable lack of clarity around when a person's immediate rehabilitation needs following an event leading to an acquired disability become ongoing rehabilitation. NDIA has capacity to fund longer term rehabilitation (e.g. from registered nurses, physiotherapists, speech therapists, psychologists, and social workers), but not where this is more appropriately funded through Health or other systems. The Health system, according to current practice, generally provides rehabilitation until a person leaves the acute setting, and for some people, there is limited ongoing access to therapeutic services through hospital outreach programs.

The gap between Health and Disability services and lack of consistency and fairness in pathways from acute to community care is widely recognised, and was one of the key damning facts raised by the Productivity Commission in its report into Disability Care and Support. For example in NSW, people injured by traumatic means can access specialist rehabilitation, but those who have a stroke or other 'non traumatic' catastrophic injury may not access rehabilitation at all, and may end up at home or in a nursing home with little or no specialised support.

Early intervention and rehabilitation as soon as possible after injury not only improves an individual's outcomes, quality of life, and chances of the best possible recovery, but it also makes good economic sense. The National Disability Insurance Scheme Rules 2013 appear to suggest that the Health system should be providing the required rehabilitation for participants following an injury or event.³⁷ However, when these services are not provided, this leads to increased complexity, distress, and cost in the future. The current inequities in access to rehabilitation look set to continue.

BIA NSW wishes to stress the urgent need for NDIA and NSW Health to be working together now to address this gap, or the launch of NDIA will have little impact on the existing inequity with regard to access to rehabilitation in NSW.

Rehabilitation for most young people living in nursing homes is required for their lifetime, and may serve to enable improvements in function (which in many cases may appear minor and slow, but can add enormous value to quality of life and capacity for inclusion), to maintain a certain level of function, and/or to slow the progression of a deterioration in function.

³⁶ NSW Government (ADHC) (2011), p.5

³⁷ National Disability Insurance Scheme (Supports for Participants) Rules 2013, Paragraph 7.5c(ii).

Longer term rehabilitation can require specialised clinical expertise, which is the domain of health services. Without effective partnerships with Health services, NDIA will not have the capacity to fund nor provide the specialised services required for each person's lifetime. Disability organisations do not generally have access to the clinical workforce required to provide services such as PEG feeds, catheter care, pressure issues and tracheostomy care. The Young People in Nursing Homes National Alliance argues that the framing of YPIRAC as a disability-only model saw adverse effects for many participants because of a lack of Health and clinical involvement:

“This has resulted in adverse health incidents that should have been avoided; deterioration in the functional ability of residents; and sadly, some deaths. ... In every case, the disability service provider acted with the best of intent and delivered care to the best of the provider's capacity. It is simply that disability services, by itself, did not have the expertise or capacity to deliver the suite of responses (including clinical responses) these residents required.”³⁸

The NDIA Rules state the following:

7.4 The NDIS will be responsible for supports related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living, including maintenance supports delivered or supervised by clinically trained or qualified health practitioners where these are directly related to a functional impairment and integrally linked to the care and support a person requires to live in the community and participate in education and employment.³⁹ **Disability services operating within NDIA will need the support and input from NSW Health funded services in order to make this a reality for young people with complex needs.**

NDIA will not be available for all Australian residents until June 2018.

DisabilityCare was launched in the Newcastle Local Government Area (LGA) on 1 July 2013. Over the next two years, people living in the Lake Macquarie and Maitland LGAs will be able to access the scheme, with the rest of NSW being progressively rolled out from July 2016 to June 2018.

This means that thousands of young people with disabilities living in residential aged care and / or facing admission to residential aged care will wait up to 5 years before being considered for the program.

The implementation of Stronger Together 2 (NSW's strategy for disability services) is underway, and ADHC contemplates a seamless transition from Stronger Together 2 to NDIA, as the funding and management of disability services in NSW is handed over.

³⁸ Young People In Nursing Homes National Alliance (2013), p.15

³⁹ National Disability Insurance Scheme (Supports for Participants) Rules 2013 (as made on 18 June 2013), Paragraph 7.4.

The Chief Executive of ADHC said in January this year:

There is already significant alignment between the policy objectives of Stronger Together 2 and the objectives of NDIS design, including an emphasis on:

- embedding person centred supports in all aspects of the service system;
- a life span approach to early intervention and prevention which includes life-long planning and an expanded and more flexible range of supports;
- building the long term capacity of the system to respond to growing demand; and
- whole of government collaboration in creating an effective support pathway and the creation of inclusive communities.⁴⁰

The NSW Government has responsibility now, particularly in relation to dot point 4, if the transition is to be truly seamless.

Real housing and accommodation solutions.

We are aware that there is a serious shortage of housing supply across the Australian community, including insufficient affordable rental housing for people in low to moderate income households, and long waiting lists for community housing. Accommodation options should be explored fully, and include looking at the levels of rental subsidies and other support to enable people currently living in residential aged care to be able to live in their own home.

The Young People in Residential Aged Care National Alliance recommends a partnership approach to explore and deliver innovative housing solutions that may involve the private sector and non government housing providers, as well as existing Government programs.

For example, it recommends looking at the opportunities presented by the Federal Government's Supported Accommodation Innovation Fund (SAIF) as one means of developing these initiatives further. This program, among others, including some of the work funded through YPIRAC, has seen effective partnerships with developers resulting in capital development, offering opportunities for younger people with disabilities to live in their own home.

Other models could also be implemented in Australia, including those such as the Shared Lives program in the UK. This is a network for family-based and small-scale ways of supporting people who need support with daily living.

There are over 10,000 Shared Lives carers in the UK. They share their family and community life with someone who needs some support to live independently, including people with a disability, older people with dementia, and people with mental health problems. Shared Lives carers are recruited, vetted, trained and supported by over 150 local Shared Lives schemes.

In Shared Lives, a Shared Lives carer and someone who needs support get to know each other and, if they both feel that they will be able to form a long-term bond, they share family and community life. Shared Lives carers are paid a modest amount to cover some of their time and expenses. In Shared Lives, everyone gets to contribute to real relationships and the goal is ordinary family life. **More of this kind of thinking, planning, and implementing is urgently needed, and a great strength of Shared Lives is that it enables people in the community and people working at the grass roots to engage with the system and come up with solutions.** Opportunities are out there and good ideas being implemented now, and the NSW Government needs to be more open to innovation in order to tackle the accommodation crisis effectively. The first step is getting the right mix of stakeholders together.

⁴⁰ Jim Longley (2013), the Chief Executive of ADHC, in his Keynote address to the National Disability Services NSW State Conference

The need for collaboration.

“The fact is that no one area of the service system can deliver the full suite of service responses the YPINH require. This means that it is essential for the NDIS to partner and collaborate with other program areas around development of services needed. This is not only fundamental to the reform imperative the NDIS should embrace; it also makes good social and economic sense.”⁴¹

With the NSW Government now disbanding the funding and service role of ADHC, the only agency with responsibility for disability services in NSW will be NDIA.

The NDIS Act and the various Rules and Operational Guidelines do not go into any detail about the NDIS’s interface with ‘other service systems’, only to say that the CEO may consider what other service systems may be able to provide when making decisions about a participant’s reasonable and necessary supports.

The risk associated with this is that the opportunities that are available through formal partnership and joint planning between NSIA and these ‘other service systems’ will be missed. A key group of people whose needs will not be met if such opportunities are missed is younger people living in residential aged care who, in order to achieve their goals and to exercise choice and control, require appropriate accommodation combined with appropriate clinical support alongside those services offered by NDIA.

The state-run services of Health and Housing must work alongside NDIA to make this real.

The Young People in Nursing Homes Alliance, recommends, in relation to collaborative partnerships, the following:

- Develop discharge protocols that ensure rehabilitation is an inherent part of support packages for participants on exit from acute care [requiring Health involvement];
 - Develop protocols with aged care to ensure rehabilitation services can be delivered in aged care;
 - Develop proactive partnerships with health re delivery of rehabilitation, nursing and allied health resources in the community;
 - Develop partnerships with allied health, housing, families and disability agencies to deliver alternative supported accommodation options.
- and
- States and Territories Community and Disability Services Ministers must lead negotiations of cross program protocols around the YPIRAC2 initiative with relevant portfolio areas within their jurisdiction as part of a national framework developed by the YPIRAC2 initiative.

10. Conclusion

YPIRAC2, a visionary document compiled by the Young People in Nursing Homes National Alliance, articulates some recommendations for continuing the work of YPIRAC while incorporating the ‘lessons learnt’. BIA NSW asks that these recommendations be fully considered as part of both the short term and longer term plans for addressing the young people in nursing homes issue.

⁴¹ Young People In Nursing Homes National Alliance, opening statement to the Senate Community Affairs Legislation Committee Inquiry into Disability Care and Support, January 2013

Australia needs a long term strategy to properly address the issue of young people with disabilities living in residential aged care.

NDIA is part of the solution, but it is not the whole solution, and for most people, it is not here yet.

- NSW needs a cross-portfolio partnership approach, incorporating Disability, Health, and Housing agencies.
- NSW needs a high level approach to infrastructure development to build capacity in the supported housing system, and a whole-of-government approach to the need for people with disabilities to achieve their goals and aspirations.

YPIRAC demonstrated that, with well directed strategies, significant improvements can be made in people's lives. This work must continue, and be strengthened by the lessons learnt from YPIRAC, together with the new opportunities presented by the NDIS, and the engagement of other government and non government agencies.

A comprehensive plan needs to be developed now to address this issue for the longer term, ensuring robust engagement in planning and implementation with all the stakeholders identified in this submission.

NSW, led by its Disability Services Minister at the time, the Hon. Andrew Constance, was proud to lead the way in Australia in being "NDIS-ready" and being the first state to reach an agreement with the Commonwealth, thanks to the resourcing and vision of the Stronger Together strategy. Implementing a robust solution to meet the needs of the cohort of younger people living in nursing homes would enable NSW to proudly lead the way once again, and again in an area of vital importance to its social inclusion agenda.

In the meantime:

BIA NSW urges the NSW Government to immediately reinstate the YPIRAC program, with a view to continuing its work across NSW, while incorporating the findings and recommendations of the evaluation report, as well as the work of the Young People in Nursing Homes National Alliance.

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