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Young people in aged care: progress of the current national program

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Abstract

Objective. The aim of this paper is to examine the progress and effect of the current 5-year \$244 million national Young People in Residential Aged Care program on the reduction of young people in aged care.

Method. Semi-structured telephone interviews with 20 service providers, 10 advocacy organisations and 6 public servants across Australia actively involved in the implementation of the program.

Results. The development of new accommodation options has been slow. The 5-year program aims to move 689 young people out of nursing homes; in the first 4 years of the initiative only 139 people had moved out. The lives of those who have been helped by the program have been enormously improved.

Conclusions. This study highlights the challenges of achieving a long-term reduction in the number of young people in residential aged care, including the challenge of achieving systemic change to prevent new admissions.

Implications. The accommodation options currently being developed for this target group will soon be at capacity. Without sustained investment in developing alternative accommodation options and resources to implement systemic change ~250 people under 50 are likely to continue to be admitted to aged care each year in Australia.

What is known about the topic? Prior to the current 5-year, \$244 million, national Young People in Residential Aged Care program there were more than 1000 Australians under 50 years of age who lived in aged care facilities. Aged care is not designed or resourced to facilitate the active involvement of young people with high clinical needs in everyday activities or support their continued participation in the life of their community.

What does this paper add? In the first 4 years of the national program only 139 people moved out of aged care. The lives of those who have been helped by the program have been enormously improved. The program is unlikely to result in a long-term reduction in the number of young people in aged care.

What are the implications for practitioners? Systemic change and sustained investment in accommodation options is required to resolve the issue of young people in aged care.

Additional keywords: accommodation, disability, housing, support.

The inappropriate placement of young people in residential aged care (RAC) is an international issue. ¹⁻⁹ In the United States the percentage of residents younger than 65 years is increasing. ^{6-8,10} A recent study found that young people in RAC spent most of their time alone or watching television. ⁶

In Australia, the 5-year national AU\$244 million Younger People in Residential Aged Care Program (YPIRAC) commenced in July 2006 and is in its final year. ¹¹ This initiative is one of the largest to be undertaken internationally. The initial priority of the program was for people under 50 years of age. ¹² The national targets for the YPIRAC program are outlined in Table 1. The purpose of this paper is to evaluate the progress of the national YPIRAC program and its effect on the long-term reduction of young people in RAC.

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Table 1. Progress made towards the three objectives of the Younger People in Residential Aged Care Program (YPIRAC) program in the first 3 years

Objective	Progress	% achieved
Objective 1. Net reduction in the number of young people with disability under the age of 50 in Residential Aged Care (RAC) of up to 689 (i.e. 325 people under 50 left in RAC). ⁴⁰	There were 1007 people under 50 in RAC in June 2006 and 715 in June 2010; 139 people moved out 18	42%
Objective 2. Up to 288 people under the age of 65, who are at risk of admission to RAC, to be provided with services to divert them from inappropriate admission to RAC. ⁴⁰	207 people diverted from RAC. ¹⁸	72%
Objective 3. Up to 247 people under the age of 65 to be provided with enhanced services within a RAC setting, where RAC is the only available, suitable supported accommodation option. ⁴⁰	409 people provided with enhanced services. ¹⁸	166%

The majority of people under 50 years are aged between 40 and 49 years. ^{13–17} For 6 years before the current YPIRAC initiative in Australia the total number of residents under 50 was similar, ~1000. ^{13–15,18} However, this population is not static, ~250 people under 50 were admitted to RAC each year. ¹⁸ The overall numbers did not increase on an annual basis largely because people either died or turned 50. ^{19,20}

Over the past 20 years there have been a range of reports and studies specific to the social exclusion of young people in RAC. Early literature was based on anecdotal evidence and consultations rather than formal rigorous research. ^{21–24} Young people in RAC are a difficult population to access for research, there are often only one or two young people in each RAC facility and many are unable to respond to written communication. ^{4,25} Several studies have utilised surveys of RAC managers to obtain information about the characteristics of young people in RAC. ^{4,20,26,27} These surveys have revealed that young people in RAC are not a homogenous group, they have a range of disability types including acquired brain injury (37%), multiple sclerosis (17%), intellectual disability (15%) and Huntington's disease (7%). ⁴

Several studies have documented the social isolation from peers^{2,21,24,28} and lack of appropriate leisure activities^{21,27,28} as significant issues for young people in RAC. The most recent study found that 53% received a visit from a friend less often than once per year and 45% almost never participated in community-based leisure activities.²⁵

A study that aggregated the assessment and planning data from YPIRAC participants in Victoria found that 36% of young people in RAC required the highest level of support, indicating they cannot be left alone and require nursing care or surveillance 24 h per day. ²⁵ This report also found that 65% of young people in RAC wanted to explore alternatives to living in RAC. ²⁵

The YPIRAC program is the first nationally coordinated attempt to respond to the complex needs of this highly vulnerable and neglected group. At the start of the program in June 2006 there were 1007 people under 50 living in RAC. From June 2006 to July 2009 there were 878 new admissions of people under 50 into RAC. In the first 4 years of the YPIRAC program (1 July 2006–30 June 2010) 1141 people received services (including some people who had an assessment and are waiting for services). Table 1 outlines the progress made towards the three aims of the YPIRAC program in the first 3 years. The YPIRAC program has exceeded its target related to the provision of enhanced services to young people who remain in RAC. The

enhanced services provided to people remaining in RAC included attendant care/personal care (accessed by 20% of users), community access (other than day programs) (18%), assistive products and technology (17%) and individual therapy support (16%). In the first 4 years, the program achieved 72% of its target related to the diversion of people at risk of admission to RAC and 42% of its target related to the net reduction of people under 50 in RAC.

A mid-term evaluation commissioned by the federal government found that the YPIRAC program has had a positive effect on a large number of young people in RAC.²⁹ Similar to previous studies, 21,22 this evaluation identified that a significant barrier to the development of services for this group was the lack of collaboration between the housing, health and disability sectors. Ryan et al.²⁹ concluded that although the program is likely to meet its targets, many young people in RAC will continue to have significant needs that cannot be met within the resources of the current YPIRAC program. This evaluation, commissioned by the Department of Families, Housing, Community Services and Indigenous Affairs, involved in-depth telephone interviews with the respective program managers from the Commonwealth, State and Territory Governments implementing the Council of Australian Governments (COAG) initiative.²⁹ The number of participants interviewed is not specified and the findings of this report may be based on as few as nine interviews.

In April 2010, the Summer Foundation was engaged by the Department of Human Services to undertake a Quality of Life Evaluation for individuals participating in the Victorian component of the national YPIRAC initiative called 'My Future My Choice'. This evaluation is currently obtaining the perspective of both YPIRAC participants and their families on the outcomes of this program and is due for completion in January 2012.

The current YPIRAC program is an opportunity to make a significant difference to the lives of a group of people who are currently marginalised in our society. This initiative is an opportunity to demonstrate pragmatic, cost-effective, viable alternatives to young people living in RAC and to develop innovative services. The aims of the current study were:

- 1. To obtain the perspective of a range of workers involved in the implementation of the national YPIRAC program on the effect of this initiative and key learnings in the first 3 years of the initiative
- 2. To examine the effect of the current initiative on the long-term reduction of young people in RAC.

322 Australian Health Review D. F. Winkler et al.

Method

Design

The prospective study utilised semi-structured telephone interviews.

Participants

Participants were health professionals, disability workers, advocacy organisations and public servants in each State and Territory of Australia who were involved in the implementation of the current national YPIRAC program. Initial participants were identified by reviewing the authors of relevant journal articles and presentations in the past 5 years, the National Young People in Nursing Homes Alliance website (see www.ypinh.org.au, accessed 15 July 2011) and the State, Territory and Federal government websites that provide information about the YPIRAC program. A snowball sampling technique³⁰ was then used; each informant was asked at the end of the interview: 'do you have any suggestions for other people I should interview in your State or Territory?'

The response rate to this sampling technique was 59% with 36 informants drawn from a range of organisations across Australia including advocacy organisations (10 people), service providers (20 people) and disability services within State government (6 people). Most (69%) of the informants were female. Table 2 shows the spread of informants across States and Territories (Table 2).

Data collection

Data were collected via semi-structured telephone interviews that were audio-recorded. The interviews were conducted from April to July 2009. The mean length of each interview was just under 15 min with interviews ranging from 8 to 22 min. Interviews obtained the informants' perspective on the progress of the initiative, the 'key learnings' from the first half of the program and their perspective on the future focus of service development for this target group within the current initiative and beyond (see Appendix).

Procedure

Ethical approval for the project was obtained from the relevant university ethics committee. Potential participants were invited to participate in the study via email. A copy of the transcription was emailed to the informant for review before inclusion in the data analysis.

Table 2. Location of informants

State or Territory	Informants
New South Wales	6
Victoria	7
Queensland	5
Western Australia	5
South Australia	3
Tasmania	3
Northern Territory	4
Australian Capital Territory	3
Total	36

Data analysis

The primary method of data analysis entailed coding data into meaningful conceptual units and then examining each category for shared tenets. This process was enhanced using NVivo 7.0.³¹ Pseudonyms were allocated to participants.

The inductive analysis process was completed using the participants' own words taken from the interview transcripts. The rigor of the study was enhanced by conducting member checks with the participants. After the initial data analysis phase was completed, each participant was emailed a three page summary document outlining the overall results of the study (i.e. summary of the main themes) and some questions to obtain their comments and concerns about the preliminary findings. The member-checking process identified a high level of support for the key themes, thus ensuring that the results were reflective of the participants' perspective.

Findings and discussion

Moving young people out of RAC

In the first 3 years, seven new accommodation options were built across Australia, and 92 young people moved out of RAC. Participants reported that not enough accommodation and support options will be developed in this initiative to meet the current needs of all the young people living in RAC or at risk of admission, let alone meet future demand.

There should be ongoing growth at building these facilities because once you pull out a group of people from the hospital system and nursing homes and build the facilities and put them in, they are full and because they are well cared for, they last longer. [Sharon, WA]

Similar to Ryan *et al.*²⁹ the current study found that the YPIRAC program is unlikely to result in a long-term net reduction of young people in RAC.

Young people in RAC have a diverse range of support needs and preferences for accommodation and support. ^{25,32} However, respondents reported that the YPIRAC program was not developing the variety of accommodation and support options required to support the wide range of individual needs and lifestyles.

I held high hopes for there being some really creative thinking about different models... and the reality of what they've done so far in terms of moving people out of institutions is, you know, for a lot of people, they just moved them into smaller institutions. That's what's so disappointing about it. [Maree, VIC]

Respondents identified the need for a range of accommodation options including individualised funding to remain living at home, as well as timely access to social housing and disability support packages, clusters of units or apartments with some common areas for recreation and social interaction in addition to group homes. Participants also reported that within the YPIRAC program there needs to be more scope for developing options that are tailored to the specific needs of an individual and their family.

So I think let's be a little bit bold and speculatively build a range of options, certainly tapping into the [housing] stimulus package that's out at the moment. [Tony, WA]

The findings indicate that most of the services being developed are group home or congregate care models where people have no real choice in where they live, or with whom they live. The limited range of options being developed in the YPIRAC initiative is out of step with the policy aspirations in the disability sector, which focus on person-centred planning and state that people with a disability should be able to choose where they live, with whom, and in what type of housing. 33,34

Diverting young people with who are at risk of admission

Respondents reported that less young people wanted to move out of RAC than they expected. They observed that once young people moved into RAC they were less likely to want to move out. This may be related to the fact that social supports and connections of young people in RAC to their local community tend to diminish over time. ^{4,25,35} Several respondents believed that there should be 'more focus on the prevention of people going in'. [Jane, NT]

Most young people who enter RAC are admitted from a hospital. ^{25,32} Several participants identified the need for the health and disability sectors to develop and jointly fund new services to create pathways out of hospital for the YPIRAC target group. Kim described how disability services had started working more closely with health.

We have a joint project [with Health], which is to look at that systemic issue around that pathway through hospitals ... It won't address the gaps, but it does put us in a better position to be clear where the gaps are as opposed to we just didn't get coordinated early enough. [Kim, ACT]

Other participants identified the need for step-down units attached to hospitals and transitional living services that provide slow-stream rehabilitation. These services would give young people at risk of admission to RAC the time and services they require to recover and maximise their abilities. ^{25,36,37} They also have the potential to reduce new admission to RAC, reduce the costs of lifetime care and make better use of resources available for disability supports. ^{25,36,37} One of the key findings from this study was the importance of preventing new admissions to RAC facilities rather than moving people out to community settings after they have been admitted.

Enhancing the delivery of specialist disability services to young people in RAC

Young people in RAC often lead lives that are characterised by loneliness and boredom. 4,25 Individualised support packages funded through this program have enabled some young people in RAC to participate in age-appropriate activities and access their local community. Steve stated that:

... people in aged care have limited disposable income and, to enable them to get out of the aged care to access the community, we thought we needed to contribute for their taxi fares. We've paid the massage therapy or Reiki therapy

for three people now ... the benefits have been quite amazing. [Steve, TAS]

Participants stated that the flexibility of these packages was important for some YPIRAC participants. Some funding packages were not constrained to disability supports or allied health intervention which meant that they could be used flexibly to address the barriers to community participation. Respondents reported that for some individuals, paying for a gym membership or taxi fares to attend a community group or visit family was a better use of resources than paying for disability supports.

Participants also reported that the allied health services and equipment provision funded through this program have had a significant effect on the lives of some YPIRAC participants. Respondents reported that the provision of wheelchairs with supported seating enabled some people to sit out of bed without discomfort, go outside and access their local community. Funding for speech pathology and communication aids enabled other people to express their basic needs and preferences.

However, when the current initiative concludes in July 2011, this target group will revert to being dependent on the RAC facility and their own resources to fund aids and equipment while they live in RAC.³⁸

Limitations of the current study

This study only provides an evaluation of the first 3 years of the 5-year initiative. An evaluation conducted late in 2011, would provide a more comprehensive picture of the effect of this program. However, decisions regarding the possible extension of the current program are likely to be made by the Federal and State or Territory Governments early in 2011. Therefore, the current study provides a more timely evidence base for future services for young people in RAC. An important missing element of the current study is the perspective of people with a disability and their families. However, current research being conducted by the Summer Foundation is obtaining the perspectives of young people in RAC and their families in Victorian on the outcomes of the YPIRAC initiative.

Conclusion

This paper has found that the current 5-year \$244 million national YPIRAC program has made a significant difference to the lives of hundreds of people with a disability and is poised to affect hundreds more as many more alternative accommodation options are opened.

The current study provides a comprehensive and independent evaluation of the first 3 years of the YPIRAC program. It provides clear direction for the remainder of the current initiative and the work that is required beyond this initiative to permanently reduce the number of young people in RAC.

There are two key factors that need to be addressed to significantly reduce the number of young people in RAC in Australia. First, there needs to be a dramatic increase in both the range and number of supported housing options. Second, there needs to be systemic change to stem the flow of young people into RAC facilities.

Although the current initiative is a great start, it will not result in the long term reduction of young people in RAC. In 2006, this initiative was presented as a 'first step'.³⁹ Developing the scale and range of accommodation options required to resolve the issue of young people living in or at risk of admission to RAC will require a whole of government approach with the housing, health and disability sectors working in partnership.

Competing interests

The authors declare that no conflicts of interest exist.

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Appendix. Interview questions

		прреп	dia. Intervi	ew question			
		olvement of your org E Initiative in your S		•	ation of the Yo	oung People in	n
2. Do you ha		the targets that have	e been set for	your State or	Territory] at	the beginning	of this
Net re	eduction of YI	PIRAC					
Numb	per of people a	assisted to move out	of aged care				
Diver	Diversions from aged care						
Enhai	ncement packa	iges					
3. Do these t	argets still app	pear to be relevant a	nd appropriate	?			
	people invite	d to participate in th	ne COAG YPI	RAC program	in your State	or Territory a	and what
5. How many	y people have	indicated that they	would like to b	e part of the	initiative?		
6. What are t	he inclusion/e	exclusion criteria for	participation	in the prograr	n?		
7. How man	y people are c	urrently participatin	g in the progra	ım?			
8. How many	y people want	to explore alternativ	ve accommoda	ntion options?			
9. How man	y plans/assess	ments have been con	mpleted?				
	-	ent' packages have ssessments, etc.)?	been funded (i	e. funding fo	r equipment,	support to acc	ess the
11. How man	ny of these 'er	nhancement' have be	een implemen	ted?			
12. How man	ny people hav	e been assisted to m	ove out of age	d care?			
	oup as part of	rted accommodation the COAG initiative		been develop	oed in your St	ate or Territor	ry for this
	_ new service		T		GI.		
Location	n of beds	Organisation(s)	ABI	MS	Client group HD	degen	mix

(continued next page)

326 Australian Health Review D. F. Winkler et al.

Appendix. (continued)

14.	How mai	ny new service	es are currently bein	g developed?						
		_ new service	es being developed							
Location n of beds Organisation(s)						Client Group				
				ABI	MS	HD	degen	mix		
15.	How mai	ny people at ri	sk of admission to a	iged care have	been diverted	1?				
,	Where w	ere they diver	ted from?							
Hospital										
	Home									
	Other, please specify									
	Types	of disability								
16.		•	velopments or initial e questions above?	tives related to	the COAG i	nitiative in yo	ur State or Ter	ritory that		
17.	Are there	e any unique c	hallenges or issues s	specific to you	r State or Ter	ritory?				
18.	What do	you think are	the key learnings fro	om the first ha	alf of this 5 ye	ars initiative?				
19.	What do	you think the	initiative should foc	cus on in the re	emaining 2 ye	ars in your St	ate or Territory	y?		
20.	Do you h	ave any sugge	estions for other peo	ple I should in	nterview in yo	our State or Te	rritory?			
21.	Are you		reports or data that a	re publically a	vailable that	may assist us	with the evalu	ation of this		