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evaluation report

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Evaluation of the Younger People in Residential Aged Care Program

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Evaluation of the Younger People in Residential Aged Care (YPIRAC) Program

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1 Introduction

The Young People in Residential Aged Care (YPIRAC) program was a joint initiative of the Commonwealth and State and Territory Governments aimed at reducing the prevalence of younger people with disabilities being inappropriately placed in aged care settings.

This report outlines the findings from a small South Australian study that explored the impact of the program on clients.

1.1 The YPIRAC initiative

1.1.1 National context

Residential aged care facilities are not an appropriate option for younger people with disabilities, although they have frequently been used as the 'service of last resort' for those whose care needs can no longer be met in community accommodation. In 2006 the Council of Australian Governments (COAG) agreed to establish a new program to address this problem. A total of $244 million over 5 years was available to the States and Territories to deliver the program.[1]

The YPIRAC program had three objectives:

- For those leaving residential aged care: to move younger people with disability, subject to individual choice, from residential aged care to alternative, more appropriate, supported accommodation, where it can be made available (Program Objective 1 - PO1)
- For those at risk of entering residential aged care: to divert younger people from entry into residential aged care into more appropriate accommodation and support (Program Objective 2 - PO2)
- For those remaining in/entering residential aged care: improve the delivery of additional appropriate disability support services (Program Objective 3 - PO3).

The primary focus of the initiative was on those aged less than 50 years (referred to as 'younger people'), however the program targeted all people with a disability aged under 65 and living in or at risk of entering residential aged care (RAC).

The program was coordinated by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), with day to day management of the program resting with each State/Territory.

Under the terms of the YPIRAC bi-lateral agreement, all jurisdictions were required to report their progress and contribute to the national evaluation.

1 The Australian Government provided half of the funding with the other half coming from the State and Territory Governments.

Strategies were in place to evaluate the program nationally. A mid-term review, commissioned by FaHCSIA, was undertaken by an independent consultant (Urbis) with the report released in June 2009.[2]

The review focused on implementation, progress towards targets and other key issues. It was based on the program's data, documentation and information gathered from key stakeholder (i.e. relevant program managers and State/Territory officers).

A mid-term evaluation was also completed in March 2010 by Monash University in conjunction with the Summer Foundation. The aim of this evaluation was to assess the progress of the initiative in achieving set targets and provide 'a range of perspectives on the implementation (…), capture the shared wisdom of a range of stakeholders and provide clear directions for the development of future services for this target group'.[3] This evaluation collected information from health professionals, disability workers, advocacy organisations and public servants involved in the program.

1.1.2 YPIRAC in South Australia

A five year Bilateral Agreement with the Commonwealth to deliver the YPIRAC program was signed in July 2006. The South Australian program was managed by Disability Services, in the former Department for Families and Communities (now the Department for Communities and Social Inclusion - DCSI).

The SA YPIRAC Framework[4] provided directions for the program's implementation. The project's aim is described as follows:

> Young people with disability have improved opportunities available to them through the quality and appropriateness of the long-term accommodation and support services that they receive, whether within or outside residential aged care, leading to improved quality of life.

2 Urbis, *Mid-Term Review, Younger People in Residential Aged Care (YPIRAC) Program*, Department of Families, Housing, Community Services and Indigenous Affairs: Canberra, 2009.

3 Winkler, D, L Farnworth, S Sloan, & B Brown, *Getting out: Mid-term evaluation of the National Younger People in Residential Aged Care Program*, Summer Foundation Ltd.: Melbourne, 2010.

4 Department for Families and Communities, *Community Transition: Younger People in Residential Aged Care Programme Framework 2008-2011*, Government of South Australia: Adelaide, 2008.

The program's main goals were to:

- **Increase** the service system capacity to respond to the YPIRAC target group
- **Reduce** by 75% the number of younger people (younger than 50) living in RAC facilities in SA
- **Engage** local service providers and agencies in partnerships to establish individual clusters
- **Ensure** accommodation and support design maximise individual choice and control within the cluster/group environment
- **Develop** a variety of cluster options (6 to 7 individuals) of supported community accommodation for 50 people.

At the time of signing the Agreement, there were 501 people in South Australia under the age of 65 living in residential aged care, of whom 64 were aged less than 50 years. The YPIRAC program staff worked with individuals, families and other service providers to identify community living options, and facilitate development and implementation of transition and support plans.

The South Australian program gave priority to individuals who could be supported in a group or cluster support model, taking into account individuals' circumstances and issues such as:

- Compatibility
- Availability of housing and support
- Groupings
- Cost effectiveness
- Urgency/risk factors
- Opportunity.

However, in the early stages a small number of individual support packages were also offered.

Eight sites with group homes/cluster sites were established under the program.

These include:

- **Strathalbyn cluster site** – property owned by Julia Farr Housing Association (JFHA), opened in December 2006 and providing six individual two bedroom units with twenty four hour on-site support (provided by Community Living & Support Service Inc. (CLASS)).
- **Guerin House** at Elizabeth East, opened in late 2008, a shared home for four people. Two YPIRAC clients lived in this accommodation with two others coming from another program. The property is owned by Housing SA with support provided by Leveda Accommodation and Community Support Service.
- **Mt Gambier** supported accommodation commenced in late 2008 in a rented house for four people (three were accommodated there at the time of the research team visit); (PQA); support provided by Home Care Plus.
- **Daw Park** shared housing for four people with high support needs opened in May 2010. The property is owned by Bedford and, at the time of the evaluation, support was provided by Stanhope. Following completion of this report, support responsibility for Daw Park was transferred to Disability Services, DCSI.

The following four properties have been developed in partnership with Julia Farr Housing Association:

- **Campbelltown** – a cluster site with one duplex and two two-bedroom units for four residents opened in April 2010 (support provided by Leveda)
- **Taperoo** – a cluster site with two duplexes and two two-bedroom units, able to accommodate six residents in total, opened in November 2010 (support provided by Stanhope)
- **Park Holme** – opened in January 2010 with accommodation configuration as in Taperoo (six residents in total) and support provided by Stanhope.

The **Elizabeth Grove** site was not operational at the time data collection for the evaluation concluded in March 2011. The site will accommodate six people (in two duplexes and two two-bedroom units).

1.2 The South Australian evaluation

1.2.1 Purpose and research questions

The South Australian evaluation explored the impact of the program on participants, drawing on client file reviews and interviews with clients, their carers or guardians, and a small number of support staff.

The Research Unit, a stand-alone unit within the former Department for Families and Communities (now DCSI) conducted the study.

The following questions were explored:

- What is the profile of participants?
- What influences a person's decision to remain in or leave a residential aged care setting? How satisfied are participants with the program, with their accommodation and lifestyle?
- Has quality of life improved for YPIRAC participants?
- Does the program work differently for specific sub-groups?
- What could be done to improve the process for others?

The evaluation commenced in November 2009 with the majority of data collection taking place throughout 2010 and early 2011. This timeframe was longer than originally anticipated, due to delays in site completions and clients moving into their new accommodation.

1.2.2 Methodology

All eligible YPIRAC clients were invited to participate.

Disability Services assisted with identifying eligible individuals and distributed information letters and consent forms.

Consent was sought from the client or their legal guardian (if appropriate) for an interview and for access to their YPIRAC file. Consenting clients or their carers were then contacted by the researchers.

All interviews were conducted in the clients' home or other place of residence. The interview approach and structure was adapted to the needs of each participant. In some instances communication was based on blinking (e.g. for 'yes') or use of a communication board. Those with communication difficulties were generally assisted by their guardian, carer or a family member. A summary of the areas explored in the interview is included in Appendix A.

The file review collected demographic data, medical and accommodation history and information about the individual's goals and aspirations.

1.2.3 Participants

Forty one clients were invited to participate. Twenty five clients consented to take part (one individual subsequently withdrew consent).

File information was accessed for 24 people and twenty clients were interviewed. The four who were not interviewed either changed their mind or their health deteriorated to the point that the interview could not proceed.

If the person had a legal guardian, they were offered the opportunity to be present during the interview. Alternatively, and as appropriate (and dependent on the person's functional abilities) a support services staff member was present during an interview. Table 1 outlines the different interview arrangements.

Table 1: Client interview arrangements

Number of interviews	Who was present	Who provided most of the information
6	Client alone	Client
8	Client and carer/staff member	In 4 cases, client provided most of the responses and in 4 staff facilitated the interview by interpreting client responses (e.g. use of letter board)
3	Client and family member/s	One interview was predominantly client-led, the other two were facilitated by relatives
1	Parent alone	Client was in a room next door but unable to be present because of medical issues
2	Client, family and staff member	One interview was led by client, another assisted by staff/relative

Seven support services staff agreed to be interviewed to discuss their perceptions of the YPIRAC program.

All interviews were conducted between June 2010 and February 2011.

1.2.3 Limitations

This evaluation has a very specific focus and does not attempt to examine the overall program's performance. Instead, it looks at clients' individual experiences, their satisfaction with accommodation and support and the impact of the program on their quality of life (as reported by informants).

The extent of information obtained from each participant varied considerably depending on their capacity for communication and their cognitive abilities (e.g. ability to remember and compare pre and post entry experiences or issues). It was also difficult for some participants to direct their comments specifically to the YPIRAC program where there was an overlap with other programs or services.

No standardised tools were used to more objectively assess any changes in clients' circumstances and wellbeing.

2 Findings

The small number of participants all had different characteristics and experiences.

2.1 Profile of evaluation participants

When presenting key characteristics of participants (such as age, primary disability and the region in which they reside), a comparison is made with data relating to all YPIRAC clients (at the time of the study's commencement, June 2009). This allows an assessment of the 'representativeness' of our group.

File data for the evaluation were collected in relation to 24 YPIRAC clients (13 men and 11 women). Ages ranged from 28 to 59 years (mean = 46; median = 49). The majority (71%) were aged 50 and under (Figure 1). Seven participants were aged over 50; however most would have been under 50 at the program's commencement in 2006. At the time of the 2009 audit, 10 out of 77 (or 13%) of YPIRAC clients were over 50.

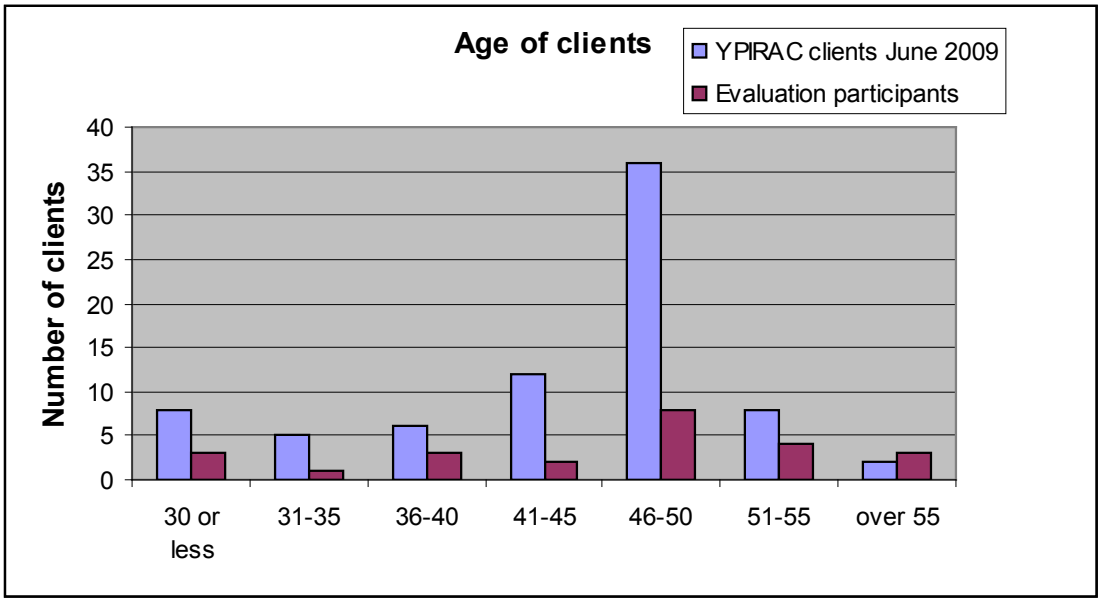

Figure 1: Age

Clients with an Acquired Brain Injury (ABI) represented the largest group for both the evaluation sample (50%) and all clients of the program (39%), followed by those with neurological disorders (33% and 36% respectively) (Figure 2).

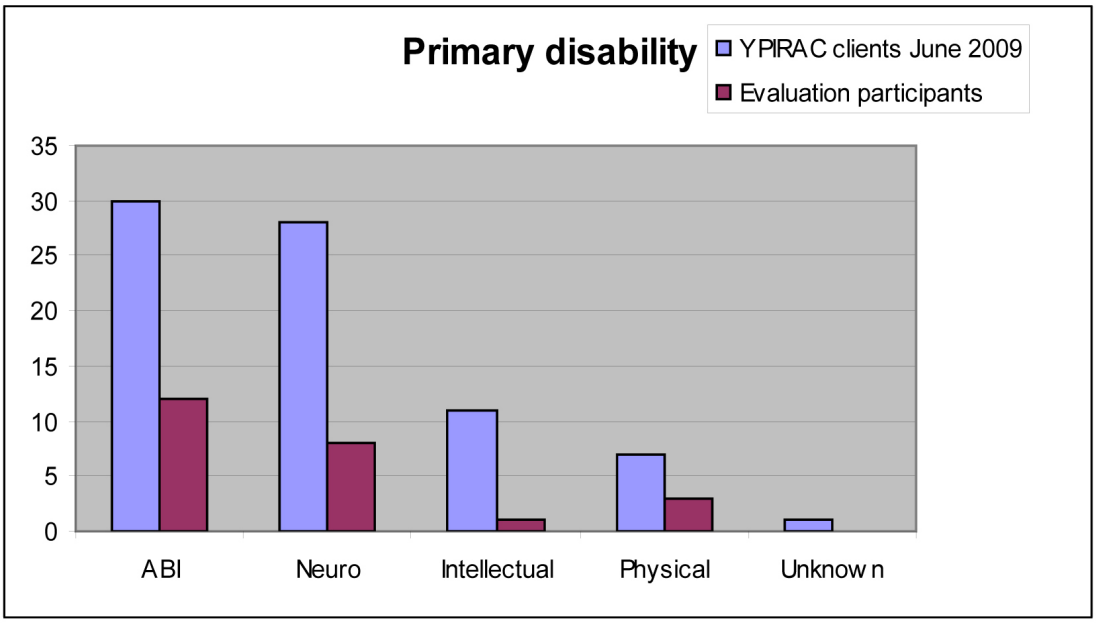

Figure 2: Participants' primary disability

Most participants (71%) were located in metropolitan Adelaide, predominantly in the central and northern regions, reflective of the locations of YPIRAC accommodation.

Attempts to recruit evaluation participants from the Northern country region were unsuccessful.

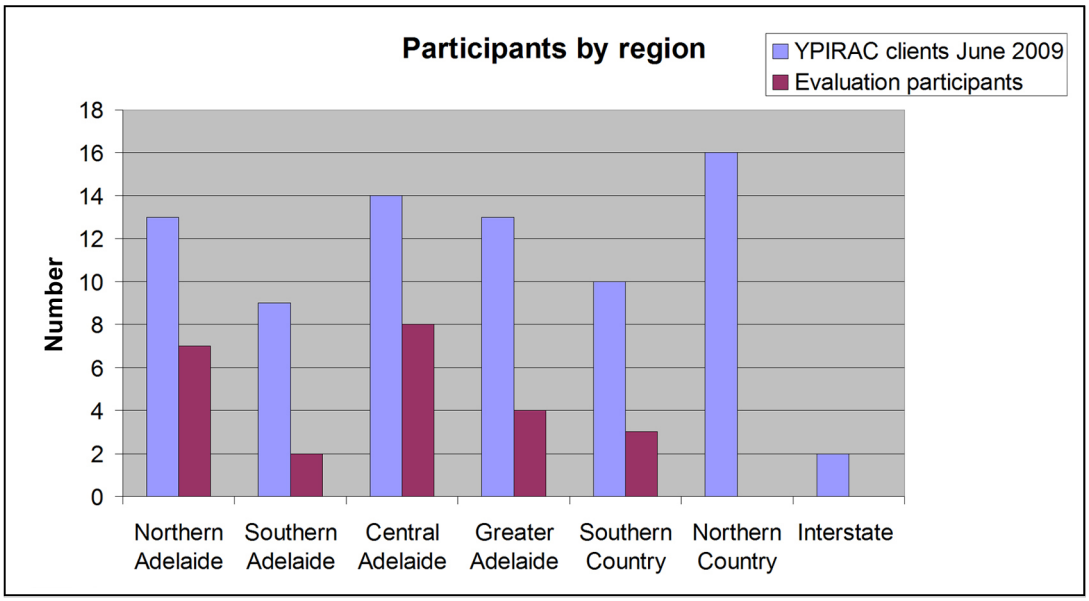

Figure 3: Participants by region

All three program streams were represented in the evaluation sample, with 11 participants involved in PO1 and the same number in PO2 (or 46% each). However, only two clients were recruited from the PO3 stream (8%). In the 2009 sample these proportions were 38%, 41% and 21% respectively. Most clients in the PO3 stream were located outside metropolitan Adelaide and did not consent to take part.

2.1.1 Medical and other needs

Information about individuals' medical and support requirements were recorded on their files. These data highlighted the complex nature of people's needs, including the reliance on 24 hour care, mobility issues and the need for support with basic daily activities such as feeding, drinking and personal care. A range of secondary health problems were identified, ranging from epilepsy, hypertension and continence issues to HIV, liver disorders and obesity problems. Mental health problems, such as anxiety and depression, were often noted, as were behavioural issues.

2.1.2 Accommodation history

At the time the evaluation ended:

- 18 people were living in a community setting (share/cluster accommodation) funded through YPIRAC
- 1 person lived on his own with a YPIRAC funded support package
- 2 people remained in RAC with a Life Enhancement Package (LEP)
- 1 person moved to Highgate Park[5] (HGP) (from RAC) as the level of care required proved to be too high for a community setting
- 2 people were residing in RAC awaiting their move to the community.

Only a third of participants had been residing in their YPIRAC accommodation for more than a year. Nearly half (46%) were there for less than a year (Figure 4), with three participants moving in late 2010 (just before evaluation interviews were concluded in early 2011). Two people moved after the interviews were completed.

Three clients in the 'other' category included two who lived in RAC with a LEP (and therefore have not moved) and one who moved into Highgate Park, as independent accommodation was deemed unsuitable at a very late stage.

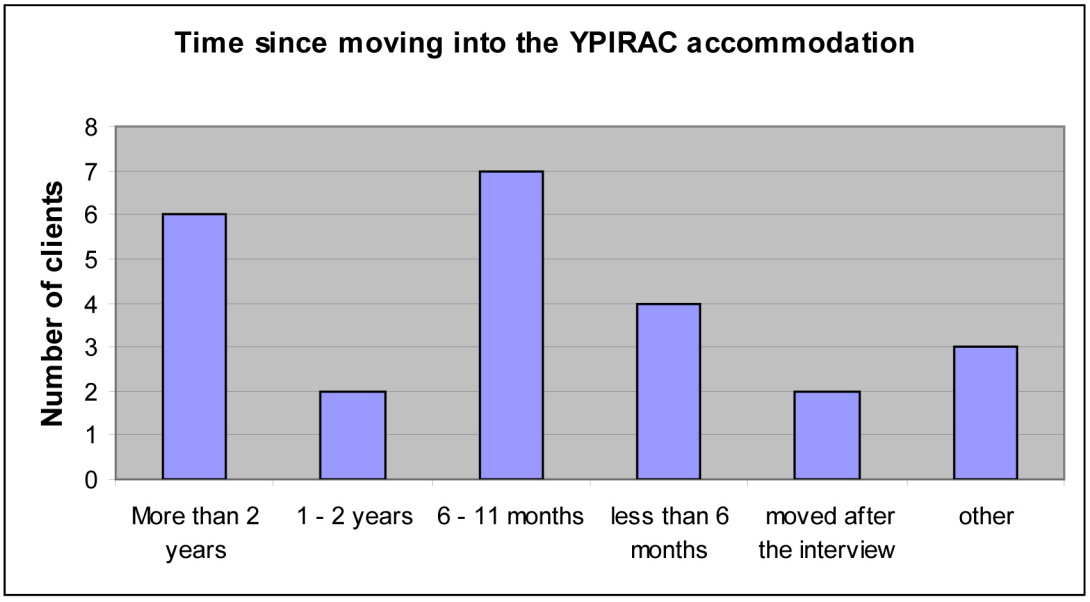

Figure 4: Time since moving into the YPIRAC accommodation

5 Highgate Park is a Community and Home Support SA campus providing a range of services, including residential care for people with acquired brain injury or neurological conditions who cannot live independently.

Many participants had experienced a number of different accommodation arrangements over the years. Immediately prior to moving into their YPIRAC housing, eight lived in Highgate Park (two in residential aged care), eleven in a residential aged care facility,[6] three in their own or family home, one in hospital and one in supported accommodation. Those living at Highgate Park had lived there for between four and twelve years and those in RAC for between three and five years, as well as one individual who lived there for sixteen years.

2.1.3 People's aspirations

As part of the assessment and planning process, individuals completed a 'My story' book that included a section on their aspirations, hopes, aims and wishes.

Most wanted to move out of RAC:

> '<Name> very much wants to move out of a nursing home - would prefer a unit over a shared house.'

Fear seemed to have influenced the decision of one person to remain in their RAC:

> '<Name> happy in the (RAC) - becomes anxious and fearful at the thought of having to move out.'

Most people wanted to live independently, with share accommodation often being a second choice:

> 'Ideal living situation would be at home, however <location> is acceptable.'

Location was important, with many participants hoping for a place close to their family or in their community or town of origin.

How services were delivered was important:

> ' <Name> wants personal space/dignity, inclusion in decision making.'

> '….wants to have freedom of choice.'

> '<Name> wants to be understood, treated as fully functional human being; wants to be consulted and asked for opinion.'

Some had very simple wishes:

> '…to be able to watch TV, go to a pub, play pokies and have a meal (out).'

> '…spending time with family, enjoys outings and recreational programs; wants to be involved in meal planning; would like to share with someone who is outgoing but not too noisy, able to respect privacy of others.'

6 Two YPIRAC clients remained in the RAC accommodation with additional support.

Remaining as independent as possible was important:

'To be able to eat and be more coordinated.'

'Control own wheelchair.'

The ability to pursue interests and social and recreational activities was also frequently mentioned:

'... attend musical events.'

'... maintain community activities and interests, attend church.'

'... get out and about; get involved in leisure activities using computer, spending time with family.'

2.2 Decision making

The evaluation explored reasons behind a person's decision to seek YPIRAC accommodation or remain in residential aged care.

Only two participants chose to remain in RAC, with additional support provided by YPIRAC. Their choices appear to have been made on the basis of familiarity (both had lived in their current accommodation for an extended time), predictability, safety, and preferred lifestyle:

'It was my choice to stay here. (…) I like to be in my room and watch television.'

'Safety. (…) There's always someone around if you need them.'

However, for others who were living in RAC, the YPIRAC accommodation was an opportunity they hoped for:

'I did not like living with so many old people, even though I am 50.'

'This place is like a prison. They treat me like an old person. I used to have an old lady walk into my room all the time. People are dying right, left and centre around me.' (client still awaiting transition)

The need to find more suitable accommodation was often driven by relatives or someone else who was advocating on the client's behalf:

'My sister made the decision for me to come here.'

'Mum found out (about the program).'

'I tried to kill myself and the psychiatrist then made it happen that I could move here.'

Some could not remember what led to the decision.

'I was approached by Disability SA and offered a house.'

A few moved into the YPIRAC accommodation from the home they owned or shared with family. The decision to move was often influenced by factors such as their deteriorating health and increased care needs or changing family circumstances. While, for some, the offer provided the right solution at the right time, others mourned the loss of their own home and viewed the move as the only option available:

'Apparently the other alternative to moving into this home was to go into a nursing home. There weren't any more hours available for service if I remained at home.'

One client indicated at the time of the interview that he 'did not want to come here' expressing preference for his previous accommodation in residential care (although he had previously chosen to move out of RAC).

Location was an important factor in decision making, with proximity to people's own community or to family a significant component:

'I lived here all my life.'

'I came from near here originally and my sister is not far away.'

Some participants turned down an earlier offer of housing because it was too far from where they wanted to live.

There were some however, who wanted to move away:

'My Mum is too close to me here! I am nearly 50 and she still tells me what to do!'

2.3 Satisfaction with the program

Overall, the vast majority of the participants expressed a high level of satisfaction with their current situation.

'This is the closest thing you can get to a home.' (parent)

'I'm happy here, it was a good decision (to move).'

'I love living here…'

'Very happy (living in the current accommodation).'

'Everything here has been wonderful. The staff have been great. They treat <client> like a human being – from the heart. I used to cry a lot, but not anymore. This place is his home and he's well looked after. I hope he stays here forever.' (parent)

Two were unhappy with some aspects of their experience and a few others identified specific issues, but overall most were happy with the program. Participants' views on different aspects of the program will be considered in the following sections of the report.

2.3.1 Physical environment

Most of the program participants were accommodated in new purpose-built units (individually or in duplexes) or purpose built or refurbished share houses (with the exception of the Mt. Gambier house).[7] One client with an individual package of support lived in rented accommodation.

Overall, there was a high level of satisfaction with the physical aspects of where they lived:

'I like this place. I've got big space, a big yard. I like the kitchen and sitting room and I have got a big bedroom.'

'The current location is fantastic.'

'I like that there is sunlight and it is a lovely, nice place. I can go outside all the time.'

'I like that there is sunlight and it is a lovely, nice place. I can go outside all the time.'

(For one client with more limited communication, an eye blink to a question posed by a parent) 'Are you happy here?' 'Yes.'

Another client became quite agitated when a question was asked about his previous accommodation and required reassurance that he was not returning there.

There were a few exceptions. One participant preferred living at Highgate Park because of its size.

'It is too small here.'

Another, who moved to cluster accommodation from independent living, was also disappointed:

'I don't like it – because I used to be in my own home and I would rather be there.'

There were also specific issues raised:

'My room is tiny here… It is hard to get into it with the chair. In hospital I had a lovely big room.'

'Too hilly, bad driveway.'

7 The Mt Gambier House was rented and not considered entirely suitable by staff and clients/relatives. Having received confirmation of on-going funding, steps were underway to look for an alternative, more suitable and permanent residence.

'I'm able to have some of my own furniture in the house. My table and chairs. I'm happy here…'

The ability to have some of their own furniture in the new accommodation or being involved in furniture selection helped make the place their own.

However, there were occasions when this sense of control and ability to choose was undermined by the support staff's approach. In one location a piece of furniture was removed from the client's area without consultation:

> 'The only disappointment is that there used to be two couches here. Then I came here one day and one of the couches was gone. We need more sitting space for visitors.'

The client and family member raised this mainly as a practical issue (as not having enough sitting space for visitors) but it also raises the issue of ownership, consultation and decision making.

Local amenities were an important consideration. In one location, the lack of open public space in the vicinity was a problem, as there was nowhere to go for a walk when relatives were visiting. In another, the proximity to the beach was seen as an asset.

Access to transport was important, particularly for those outside the metropolitan area.

> 'There is no bus service to Adelaide on the weekend…if catching a bus to visit Mum, I have to get up at 5am.'

However, the most important consideration for many was to be close to their family and community as it allowed for easier and more frequent contact.

Few comments were made about the physical environment by those who chose to remain in RAC, except for the lack of privacy.

Lack of privacy was also mentioned as a potential issue by a staff member in share house accommodation:

> 'Lack of privacy may sometimes cause problems. When people visit, everybody in the house knows it, and everybody hears what you are talking about. That's a kind of compromise in a way. I guess it is like sharing everything with your family.'

However, this issue was not raised by residents or relatives.

2.3.2 Compatibility of residents

Group and cluster accommodation, chosen as the preferred option for the project, means that in some circumstances residents share common areas (like kitchen and living spaces) and live in close proximity to one another. This offers the opportunity for positive interaction with peers (one of the issues identified as a problem in RAC accommodation) but also poses challenges with regard to the matching of residents, and resident choice (most of us expect to be able to chose who we live with).

> 'It is really important that the right people are handpicked to live together in accommodation like this.' (from relative who was happy with the situation)

It was clear from participants' comments that compatibility was something carefully considered by Disability Services staff and that, in some cases, alternative sites were offered.

Consequently, for the vast majority there were no major issues. In some locations, residents as well as their relatives got on very well:

> 'Clients in the house are all around the same age. Their interests in music, clothes, television are similar.'

> 'They're like family – even the families of clients all interact well.'

In a number of sites little interaction was reported:

> 'There are four residents here. There is not much interaction between them, but it is not a problem.'

> 'There are three residents here at the moment and the other two residents don't like to interact.'

> 'I don't really socialise with the guys – however, I never expected that.'

For some this was a significant disappointment:

> 'I'd like to have some company – I hope the other room in this house can be for a housemate. … Hopefully someone else will move in soon.'

One person felt they were not compatible with their neighbours:

> 'I think they have matched the wrong people for this program. The guy … – he has different care needs. The others need much more care than I do. One of them has schizophrenia and uses bad language – it's just that I'm not used to that.'

In a more extreme case, one resident found it particularly difficult to share a duplex with another.

Her housemate was at times aggressive, forcing her to retreat to another unit. This seriously compromised the client's sense of having her own home. A range of factors contributed to the problem, including her delayed arrival (giving the other a sense of 'owning' the unit), limited opportunities for recreational activities in the community (due to Christmas and New Year break) and the two spending considerable time together; but clearly there were also underlying compatibility issues. As the clients had only been living together for a short time, the on-site staff was hopeful that things would improve over time.

Compatibility was often raised in staff interviews and strong views expressed on what would and would not work:

> 'Certain demographic groups would need to be grouped together, rather than housing people with Huntington's and mental health issues, with other clients who have different forms of disabilities.'

> 'Having the right personality mix is also important, as well as matching people with high level needs.'

> 'Blending people who are not cognitively sound with those that are would not work well. However, it is also important to consider that people's health needs change, so planning needs to be in place to ensure that house dynamics are considered when these changes happen. Strategies need to be in place for the future.'

'Proper matching within the house is important, rather than excluding a particular group from the service.'

It was also emphasised that consultation is needed regarding the suitability of clients for shared accommodation and for a particular site.

> 'And you need the right sort of carer – the right staff.'

2.3.3 Care and support

Generally, clients and family members expressed a high level of satisfaction with staff and the support provided.

> 'Staff is very good here. Support is very good.'

> 'The best thing about this place is the carers. They always take things upon themselves to help. They are excellent.'

> 'I can't speak highly enough of the carers here. They work with such good humour.'

'People are available to help whenever I need them, whenever I press the buzzer.'

Some of the issues raised related to staff skills and manner, staff turnover, and the level of support available:

'There are some good staff members but some of the others are not highly trained. This is high care here – they have to be prepared.'

'It's the little things – staff members always ensure that <Name> has hair dyed, fingernails done, as they know it is important to her. In previous arrangements, staff simply wouldn't have the time to do this.' (parent)

'The carers are good, but they are cranky and can be bossy at times. Sometimes I complain and usually I get a good response. Quality of care is good though.'

'I don't like (service provider). There are always staffing issues. They often don't have the right staff and are short-staffed. I don't always get the care when I need it.'

'It is mainly about staff. Sometimes, there is only one staff member here, which means that you can't get people up.'

'The support hours I get don't give time for people to clean properly.'

One client reported that there was no clarity as to who can provide assistance with some issues, like repairs:

'It is hard to know who to talk to, everything takes so long. … there is a long trail of people before anything gets done. You speak to your carer, who speaks to the supervisor, who speaks to the coordinator, who then passes it on to someone else…and nothing gets done.'

One client also raised concerns about being kept informed about organisational decisions:

'When decisions are made they are not explained. You just hear it from the carers. Like when there are changes in the carers' hours and who is on the shift, it is not explained.'

I do have a say in what I do when I am going out and things like that, but there could definitely be more discussions about staffing, hours and funding and things like that.'

Staff comments focused on different approaches to the support and care provided.

'Clients have a huge say in what happens in the house such as deciding on food, doing some shopping, where the furniture goes.'

'The continuity of care is fantastic. For example, when one of the clients has to go to the hospital, a staff member will go with them and stay until they are settled. That doesn't happen in other places – where the ambulance would just get waved goodbye.'

'There is a good staff/client ratio which allows for a high level of personal care and getting to know the clients and their individual journeys.'

'The nature of the people that work here enables positive outcomes. Staff are very approachable, and new ideas and suggestions are always considered.'

'In this environment we are able to get to know and understand people much better.'

2.4 Quality of life

In this evaluation, there was no attempt to measure quality of life in a formal way (by any of the existing standardised measures). Instead, respondents' comments about people's general sense of wellbeing and satisfaction with their circumstances were considered.

On the whole, comments indicated improvements to quality of life. Aside from general satisfaction with their physical environment and support provided through the program (discussed earlier) there were also significant changes to people's sense of freedom and independence, improved opportunities for social interaction, and improvements to general health and wellbeing.

The ability to make choices and be involved in decision making contributed to an increased sense of control. The term 'freedom' was used often: the program offered a sense of liberation from the restrictions of residential care, brought them closer to a 'normal' lifestyle which, despite their physical constraints, allowed them to achieve a level of independence.

'I can now do what I want, when I want, which is very important.'

'I've started being able to do things on my own, like catching a cab to visit Mum. At last!'

'Freedom - like today - I went out to lunch. Doing what you want to do. Here you can go out quite often.'

As compared to living in the nursing home, the situation now is:

> 'Much better…more independent.'

> 'I am self-sufficient.'

> 'I go out quite a bit here – a fair bit more than before. I like that there is sunlight, and it is a lovely, nice place. I can go outside all the time. Getting out and about is different – it is my choice where I go.'

In one location, staff commented on the circumstances of a resident who previously had very little control over their life due to a problematic relationship with a parent. The resident gradually gained confidence to make decisions about her own life, whether to go to church, what to eat for lunch, buying and choosing her own clothes, and choosing to do things that are important to her. The staff believed that this would never have been achieved in a RAC environment. The parent of another client commented on how her daughter was able to plan and hold her own 50th birthday party – with the help of staff, designing invitations, inviting guests, decorating the house – taking control of all aspects of planning and decision making.

The interaction between staff and residents was seen as key:

> 'Treating people as people, and addressing their specific issues rather than not seeing past the disability.'

The increased interaction between clients and staff was often noted:

> 'There was not the same amount of things to do at Julia Farr – there were so many people for staff to look after. Here there is much more personal contact.'

This difference in approach was emphasised by many, particularly those who moved from RAC. Their new circumstances represented a sense of normality (living in a house, having a backyard, going out shopping, etc.) in contrast to an institutional system.

> '< RAC > is run by the clock – it's 'bath, park and feed'. There is very little personal interaction – which means that vulnerable people go into their shells. It is different here – my daughter is asked her opinion and she has choices. As a parent, that is wonderful to know. Sometimes she can be really engaged – I can see the impact it is having in a really good way.'

Those able to return to the community they originally came from or move close to family were particularly happy:

> 'The good thing is we live 10 minutes walk from here.' (parent commenting on his ability to drop in at any time to visit his son)

> 'The < > brother lives only 5 minutes away.' (carer indicating regular contact)

The environment was also seen as more conducive to visitors and improved social contacts:

> 'Families are more willing to come to this kind of environment – coming here is more like hanging out as mates rather than feeling like you've 'dumped' your relative in an institution.'

Generally, participants reported improved social interactions and inclusion.

> 'She has the option to go outside and participate in things – that didn't happen in HGP.'

Respondents also commented on improvements to health and general wellbeing of the program's clients:

> 'Now that my daughter is here she is sick much less often – her health has vastly improved. I would often get calls from HGP to say that she was seriously ill and was in high dependency. That hasn't happened here. She has even started vocalising since being here, which is wonderful.'

> 'When <client> came here from residing in a hospital, they couldn't lie straight and had to shower on a trolley. The hospital staff didn't have time to provide physio. <Client> is now able to use a princess chair and is much more mobile.'

> '(I feel) happier and healthier.'

> 'When <client> recently visited the hospital for a spell (this happens from time to time due to the condition), the doctor commented on how well <the client> was looking. Obviously the physiotherapy and general level of care is very beneficial.'

> 'Her engagement with the outside world is now better. The other day she went to the Botanic Gardens. She goes to art shows and exhibitions, and goes shopping – she loves to shop! She's even invited to barbeques, even though she is peg fed, she's still able to be there.'

Mental health issues, common amongst the group, with many suffering depression or anxiety, seemed to be less of a problem for some:

> 'Self esteem is gained in a place like this.'

Some clients, however, at times felt lonely or bored. The lack of funding for recreational support and transport issues were raised by some staff:

> '(There are) not enough funds for the amount of taxi trips required when clients want to go out into the community.'

> 'If clients didn't have some of their own disposable money, the opportunities to go out would be limited, and therefore mental health issues would probably emerge.'

For others, the very short time since their entry into the new accommodation meant that things were not put in place as yet.

> 'We're still waiting on recreation services to be available. There should be the equivalent of 10 hours per week for each client.'

> 'Ultimately she would like to socialise more – to meet new people and have new friends, such as being part of a coffee club. It will get there; it is just that it is all new.'

Overall, however, the program was seen as making a significant impact on clients' quality of life.

> 'Life expectancy, life enjoyment and life journey is vastly improved in this kind of setting.' (staff member)

2.5 YPIRAC's processes and other issues

Clients were asked about their experience of YPIRAC processes. Many were not able to comment on this aspect because of the time lapse and/or memory problems. Some said the main lines of communication were between the program staff and their parents/guardians, who often were instrumental in connecting clients with the program. Those able to comment raised few issues.

In the early stages of the program there seemed to be less clarity about what was on offer. According to one client, it 'was a bit of a mixed bag'. Another felt that the promise of 'whatever you need you get' turned out not to be the case in the end.

On the whole, however, there was a high level of satisfaction with available information and communication and particularly with the level of consultation and involvement:

> 'There was a huge amount of discussions.'

'<Name of Disability Services worker> kept us informed. Even though we are from the country we were invited to all the meetings.'

'My daughter was involved in all the meetings and was there when decisions were made about rooms and things.'

Similarly, transition presented few issues, with most participants either satisfied or not able to recall any problems.

'Things went smoothly. Furniture was all well organised and everything was put away well. It is not often you get that.'

'It just happened. It was well organised.'

One person's experience of moving into their accommodation was marred by problems with the hot water, gas, heating and telephone service. Another reported on-going problems with a phone and computer (despite making requests for repairs). The uncertainty surrounding who should deal with these problems added to frustration.

Some commented about the long time it took for accommodation to become available. This was particularly frustrating for those who were still waiting to move:

'There is not enough information coming through. Disability SA rings occasionally or sends me a letter.'

Insufficient communication between support staff from 'old' and 'new' accommodation (e.g. from RAC and YPIRAC) was raised as an issue. Those who had been caring for clients before the move sometimes felt information should have been transferred, although not all agreed. One parent, for example, felt there was an advantage in starting afresh:

'In some ways it was a good thing as staff didn't come to this place with pre-conceived ideas or expectations about residents.'

Some issues went beyond the YPIRAC program and related to access to services or equipment:

'I know this is an issue across different disability services, but there is room for improvement. Although reviews for equipment happen regularly, it takes a long time for the equipment to actually become available (which is usually by the time a client is due for another assessment).' (staff member)

Accessing some health services (such as podiatry or speech therapy) was sometimes difficult and, according to staff, presented at times a 'quagmire' of rules. However, improvements were also noted:

'A speech pathologist now comes to the house once a month. In other places it may only be every three months.'

'There's a local dentist here, who <client> listens to. He never used to listen to the dentist when at Julia Farr.'

2.6 Other pathways

As indicated earlier, the evaluation focused on people who had moved (or were about to move) into a cluster site or share house accommodation. There were, however, four exceptions.

Two people chose to remain in the RAC accommodation and were provided with additional supports. Their decision to remain was discussed previously (Section 2.2). Both were relatively satisfied with their situation and quality of life but were not able to comment on the impact of the YPIRAC package.

One person, initially assessed as suitable for share accommodation, had to be placed in residential care at Highgate Park because their health required intensive monitoring and care. This decision was made after an extensive period, just as the client was getting ready to move into a share house, and had a significant impact on the client and family:

'<Name> was really disappointed …., is now giving up a bit.'

A range of issues contributed to this situation, including problems with stabilising the person's condition (possibly made worse through poor management in the intervening period). However, the importance of a thorough and careful initial assessment, followed by reviews if required, cannot be underestimated.

This disappointment was compounded by the fact that the move from RAC to Highgate Park did not, in the families' opinion, result in any improvements to care or opportunities for social contact:

'In the nursing home there was no opportunity for her for interaction in activities of the community. Nothing has changed here due to the lack of staff.'

The final example provides a much more positive demonstration of what can be done. This man was provided with an individual support package (available in the early stages of the program) that allowed him to return to his local community and live independently. His strong desire and determination to achieve this meant that he was prepared to take a chance and accept arrangements that did not include full time care. At the time of the interview, care was provided for 8 hours a day. Modifications to a rental property, technology, and flexible care arrangements made this possible. Three and a half years after taking this step he feels it was the right decision and he is happier and healthier as a result.

3 Conclusion and future directions

YPIRAC provided an important opportunity for people with disability and high care needs. It allowed people to move out of residential aged care and into accommodation that is more appealing and home-like, with more personalised support and greater scope for choice and decision-making. People experienced a sense of liberation from the restrictions of residential care and felt they were getting closer to a 'normal' lifestyle that allows them to achieve a level of independence.

The SA YPIRAC model focused on cluster or shared housing. This was a deliberate choice, to maximise the available resources and provide an alternative to RAC for as many people as possible. For most, results have been satisfactory and they are happy with their new accommodation and quality of life has improved.

The processes developed to support the program have worked very well. Considering the complexities, this is a significant achievement.

The evaluation highlights some of the factors that contributed to positive results. These include:

- The quality of staff
- The quality and nature of the housing
- Careful matching of residents
- Facilitating people's ability to make choices and exercise control and self determination, including through excellent communication
- Location of housing that facilitates recreation and social inclusion and participation (close proximity to relatives, friends, local community, transport, access to open spaces and recreational and shopping facilities).

The evaluation also identified some areas of risk. These include communication (for example about staff changes) and consultation (for example about furniture): a person's sense of control is easily undermined. There is a need to maintain a strong focus on a rights-based[8] model of practice and person-centred active support (currently being implemented across Disability Services). Staff training, support and supervision are important elements in on-going success.

Social participation and inclusion is also an area which requires ongoing attention. Moving from residential care to community living does not automatically reduce social isolation and create community connections. Some clients would have preferred independent living. While they appreciated the advantages of cluster housing option over residential care, they often grieved the loss of their own home and decline in independence. Considering the success of one of the people in managing to live on his own, opportunities for developing other service models should also be explored.

8 Reflective of the UN Convention on the Rights for People with Disability ratified by Australia in 2008.

4 References

Australian Institute of Health and Welfare. *Younger People with Disability in Residential Aged Care program: Report on the 2008-09 Minimum Data Set*. Disability Series. Cat. No. DIS 57. AIHW: Canberra, 2010.

Department for Families and Communities. *Community transition: Younger People in Residential Aged Care Programme Framework 2008-2011.* Government of South Australia: Adelaide, 2008.

Urbis. *Mid-Term Review, Younger People in Residential Aged Care (YPIRAC) Program.* Department of Families, Housing, Community Services and Indigenous Affairs: Canberra, 2009.

Winkler, D, L Farnworth, S Sloan, & B Brown. *Getting out: Mid-term evaluation of the National Younger People in Residential Aged Care Program.* Summer Foundation Ltd.: Melbourne, 2010.

5 Appendices

Appendix A: Interview Guide – Younger People in Residential Aged Care

Accommodation history

Current accommodation status:

Brief review of where the person has lived, for how long.

Satisfaction with different forms of accommodation they have lived in.

Service history

Identify the services (formal/informal) the person has received.

Review of Involvement with YPIRAC Program

- How clear was information about the program?

Contact with Community Transition Team – how it was made.

Planning – how it occurred and who was involved.

Choice to participate – what influenced decisions, whether choices were enabled:

- What was offered – what were the reported benefits/risks?
- What kind of services have you received? (program type, range of service)?

Making a Transition (for those who changed accommodation)

Describe the move:

- Are you happier with your current living situation than before the move?
- What were the positive aspects of moving?
- What could have been done better?

Perceptions of YPIRAC

Satisfaction with the support received:

- Overall, how much has the service helped you? Are you better off/happier/healthier?

Ideas to improve for others in a similar position:

- Do you have any advice for others who might be thinking about the YPIRAC program?
- How could it be improved?
- Would you do it again?

Conclusion

- Any other comments you'd like to make about the YPIRAC program?

Appendix B: Discussion Guide for Interviews with YPIRAC staff

Area: metropolitan/country

Type of accommodation:

Intensity of support offered:

How long in disability support:

How long with the program:

_____

Role

1. Could you describe your role in supporting client/s (resident/s)?

Impact on clients

2. What in your view are the benefits of the program?
3. Do you see any risks or drawbacks?
4. Does this program work better for some clients (individuals) more than others? If so, in what way?
5. What in your view contributes to a successful outcome for an individual and what creates barriers?

Program delivery

6. What are some of the challenges in delivering the program?
7. What could be done differently or improved?
8. What works particularly well?
9. Any other comments?