Mid-Term Review, Younger People in Residential Aged Care (YPIRAC) Program

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Note: Following the Mid Term Evaluation review of the Younger People with Disability in Residential Aged Care (YPIRAC) Program, which covered the period from July 2006 to December 2008, a new National Disability Agreement (NDA) was introduced on 1 January 2009, replacing the Commonwealth State and Territory Disability Agreement (CSTDA). This change has implications for the YPIRAC Program and recommendations in the Mid Term Evaluation Report.

As of 1 January 2009, YPIRAC Program Bilateral Agreements between the Commonwealth and State and Territory Governments were superceded by the NDA, with the exception of Program targets for years 2009 to 2011.

Commonwealth funding for the YPIRAC Program has been rolled into the disability services specific purpose payment. Under the NDA, jurisdictions are responsible for the provision of specialist disability services including service planning, workforce and sector development in relation to the services they provide.

The Disability Policy Research Working Group (DPRWG) will consider future support for younger people in, or at risk of entering residential aged care in the context of the new federal financial arrangements, the implication of the NDA and the reforms to the disability system outlined there in.

APPENDICES:

Executive Summary

This Mid-Term Review report analyses the targets, performance to date and key issues associated with the Younger People in Residential Aged Care (YPIRAC) Program. The Program is a joint initiative of Commonwealth, State and Territory Governments to provide accommodation and support to younger people with disability living in or at risk of admission to residential aged care (RAC).

Overall, the Review has found that the Program is having a positive impact on a large number of younger people living in or at risk of admission to RAC. State and Territory Governments have undertaken varying approaches to the Program's implementation reflecting the different local policy and legislative contexts in which they operate.

A Council of Australian Governments (COAG) initiative, the Program commenced with the signing of Bilateral Agreements between the Australian Government and States and Territories over several months from August 2006 to January 2007. The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) coordinates the Program nationally. An overall target net reduction of between 425-689 people in the number of younger people in RAC over five years has been established.

The Program seeks to meet three objectives:

- Program Objective One: Move younger people with disability currently accommodated in RAC into appropriately supported disability accommodation, where it can be made available and if this is what clients choose.

- Program Objective Two: Divert further admissions of younger people with disability who are at risk of admission to RAC into more appropriate forms of accommodation.

- Program Objective Three: Enhance the delivery of Specialist Disability Services to those younger people with disability who choose to remain in RAC or for whom RAC remains the only available suitable supported accommodation option.

The evaluation questions set for the Mid Term Review are:

1. Were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?

2. How is the Program being implemented in each State and Territory as set out in the Bilateral Agreements and what are the challenges and issues impacting on the Program?

3. To what extent will the funding available to States and Territories meet the demand for support required by the YPIRAC initiative?

The methodology as outlined in the terms of reference for this review included:

- Liaising with the government departments in each State and Territory responsible for implementing the YPIRAC Program to collect the required information

- Undertaking an analysis of that information

- Reviewing the Program against the evaluation questions.

This Mid Term Review has taken place within a context of:

- Implementation of the Program commencing at different times in each jurisdiction, due to Bilateral Agreements being concluded within a period between August 2006 and January 2007;

- An initial emphasis being placed on the conduct of functional needs assessments of those people in the initial target group, being people aged under 50 years and currently in RAC.

Mid Term Review - Findings

This Review finds that the Program is expected to meet its targets over the five years of the Program.

- Were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?

Given the limited evidence available regarding the YPIRAC Program target group, Bilateral Agreements made a number of assumptions regarding Program targets and timeframes based on the best evidence available at the time of the Program inception. The inaccuracy of some of these early assumptions, particularly in relation to the levels of YPIRAC client needs and the cost in providing support services, have created challenges for some jurisdictions. A number of jurisdictions have renegotiated their targets and/or the timing of funding to reflect the actual experience in implementing the Program. The Department of FaHCSIA has supported the review of targets and funding arrangements as needed.

- How is the Program being implemented in each State and Territory as set out in Bilateral Agreements and what are the challenges and issues impacting on the Program?

There have been initial delays in meeting forecast targets with some jurisdictions significantly underperforming in meeting targets for Program Objective One and Program Objective Two for the initial three years of Program implementation. This underperformance can be attributed to delays in assessing the needs of the target group, the development or modification of capital programs and contacting and/or engaging clients, particularly in rural and remote locations. The initial funding allocations in some jurisdictions underestimated the large number of high need clients and therefore the costs associated with providing support services.

Jurisdictions have benefited greatly from the flexibility in the Program design. Jurisdictions have been able to prioritise Program Objective Two, define target groups and allocate funding to reflect their policy, legislative and service delivery environments. This has allowed for the development of the Program in different ways across jurisdictions – ensuring that Program implementation is efficient and reflective of local contexts.

Some jurisdictions have built on existing government structures and service delivery models to implement the Program in genuine 'joined-up' government settings.   These approaches reflect the complexity of the Program's operating environment and the necessary overlaps across the health, disability, housing, community services and aged care portfolios. These are good practice implementation approaches that will support sustainable outcomes for clients beyond the five year cycle of the Program.

Given the complexity of the Program in responding to so many varying individual needs of clients and their families, many jurisdictions have implemented productive partnerships with non-government organisations who have the expertise and service infrastructure to support the client-group. This has produced efficiencies across the Program.

Significant progress has been achieved nationally in providing genuine individualised alternatives to inappropriate RAC for younger people with disability, in a flexible and tailored service environment. This has been achieved through the development of strategic partnerships across/within governments and with the non-government sector, in a complex service interface between health, housing, aged care, disability, community services.

Jurisdictions have developed strong informal and information sharing networks across the Program nationally, sharing experiences and resources in an environment of cooperation. This is producing efficiencies across the Program nationally, reducing the likelihood of duplication, and ensuring that solutions to common problems are shared.

- To what extent will the funding available to States and Territories meet the demand for support required by the YPIRAC initiative?

Overall, data indicates that the Program target to achieve a national net reduction in the number of YPIRAC by between 425-689, is likely to be achieved within five years, as per original Program

forecasts. This conclusion is based on data provided by jurisdictions, analysis of the net number of YPIRAC in 2006 and 2008, and the percentage of Program funding that is still to be provided to each jurisdiction. Despite early delays in meeting these targets, and particularly the inconsistency of actual targets in relation to those forecast across each of the Program Objectives, nationally a net reduction of 149 people aged under 50 years living in residential aged care has been achieved[1]. Of particular importance is that 296 (51%) clients were relocated, or have agreed to be relocated from RAC, as part of the YPIRAC Program and 125 (21.5 %) were deemed at risk of entry into RAC[2].

These findings are particularly interesting given that most jurisdictions have indicated relatively slower progress towards achieving targets for Program Objective One, as capital works have not been completed at this stage of implementation and the large number of diversions reported as part of Program Objective Two. Many jurisdictions will be unable to achieve their five year targets until years four and five, as the development of capital, which takes significant time, is finalised.

Whilst overall Program targets will be achieved, these may not represent the anticipated distribution of clients across Program Objectives, as outlined in the Bilateral Agreements.

There is significant unmet need of YPIRAC, both in the under 50 years target group, and particularly the 50-65 years target group. While the Program will make a positive contribution to this previously neglected group, many YPIRAC will continue to have significant needs that cannot be met within current funding allocations.

This Mid-Term Review has concluded that jurisdictions have made significant positive progress in implementing the Program to date. There is a body of quantitative and qualitative data to support the conclusion that the Program is having a very positive impact on younger people with disabilities who either reside in, or are at risk of entering, RAC.

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[1] This data includes young people with disability in residential aged care who have died or aged out of the Program.

[2] Australian Institute of Health and Welfare, YPIRAC Program Final Report on the 2007–08 Minimum Data Set, Table 2.1

1   Introduction

The Younger People with Disability in Residential Aged Care (YPIRAC) Program is a joint initiative of the Commonwealth, State and Territory Governments to provide accommodation and support to younger people with disability living in, or at risk of admission to, residential aged care (RAC). The Program was announced in February 2006 by the Council of Australian Governments (COAG), and represented a joint commitment by the Australian, State and Territory Governments to decrease the number of younger people with disability living in RAC.

The Program was informed by an Inquiry into accommodation for people with disabilities, held by the Senate Community Affairs Committee in 2005.

Concerns were expressed at the time about the current system's capacity to meet the needs of younger people with a disability. The report detailed the diverse and complex care needs of this client group:

The younger cohort is likely to have a significant representation of high level needs. This group includes young people physically incapacitated through road and other trauma. There are a proportion of people with an Acquired Brain Injury (ABI) as a consequence of alcohol misuse and trauma. There are also people experiencing the degenerative effects of specific medical conditions such as Multiple Sclerosis and Huntington's disease. The group is therefore more likely to represent a broader and at times more complex range of carer issues than other people who are more likely to have similar disabilities such as dementia and age related frailty.

The Inquiry heard a range of issues and concerns from witnesses which are detailed below:

- Younger people with a disability face the prospect of becoming residents in aged care facilities because no other suitable accommodation is available. Many are at risk of admission to aged care facilities because they are cared for by ageing parents and/or they have medical based needs that cannot be supported by community services.

- Staff in aged care facilities may not have received appropriate training or be skilled/experienced in caring for younger people with a disability.

- Social isolation is a grave concern for young people residing in aged care services. The Committee heard that many young people suffer from depression – this may be exacerbated by 'living with the very elderly or demented and witnessing the death of other people in their homes.'

- In facilities designed for frail aged people or people at the end of their life, there is generally a lack of rehabilitation services, specialist equipment and palliative care for those with degenerative disease and other disabilities.

- The burden on carers can be extremely high and carers may have the additional responsibility of raising a family and earning an income. It was reported that some children take on the role of caring for their affected single parent, or when the healthy parent is working.

- The impact of chronic illness and the stresses of caring on families are considerable. Support groups have found that this can lead to marriage breakdowns which can further exacerbate the care and accommodation needs of disabled people.

A series of recommendations were made from the inquiry and some of these have been addressed by the YPIRAC Program.

The Australian Institute of Health and Welfare (AIHW) notes that, as at June 2007, nationally, there were 6,613 residents under the age of 65 years in RAC, comprising 4% of all residents.[1]

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[1] Australian Institute of Health and Welfare, *Residential aged care in Australia 2006-07,* June 2008, Canberra, p 42.

1.1   Program Objectives

The YPIRAC Program aims to reduce the net number of younger people in RAC by between 425-689 people, through the implementation of three strategic objectives. These are to:

- Move younger people with disability currently accommodated in RAC into appropriately supported disability accommodation where it can be made available and if this is what clients choose.

- Divert further admissions of younger people with disability who are at risk of admission to RAC into more appropriate forms of accommodation.

- Enhance the delivery of specialist disability services to those younger people with disability who choose to remain in RAC or for whom RAC remains the only available suitable supported accommodation option.

The primary focus of the initiative is on people with a disability aged less that 50 years living in RAC, however the overall target group is people aged less than 65 years either living in RAC or at risk of admission to such care.

The focus of this Mid-Term Review is to assess whether the Program is on track to achieving its intended outcomes.

1.2   Key Evaluation Questions

The key evaluation questions for the review are as follows:

1.   Were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?

The evaluation shall examine:

(a) whether the Bilateral Agreements between the Commonwealth and each of the State and Territory Governments are structured to achieve the objectives of the initiative;

(b) whether the implementation processes of States and Territories are capable of delivering the objectives;

(c) whether it can identify the extent to which States and Territories are meeting their agreed target; and

(d) whether the data provided by the States and Territories inform COAG that jurisdictions are meeting the objectives consistently, and conclusions about the Program can be made.

2.   How is the Program being implemented in each State and Territory as set out in the Bilateral Agreements and what are the challenges and issues impacting on the Program?

In considering this, the evaluation shall:

(a) examine the challenges, issues and best practices, identified through implementation of the Program;

(b) identify how States and Territories are addressing the challenges;

(c) examine how successful measures to address challenges will be in meeting the Program's objectives; and

(d) examine implementation activities of each State and Territory Government's disability services agencies to determine outcomes in terms of:

    a. supports provided;

    b. community access;

   c. *aids and equipment;*

   d. *transport assistance.*

3. To what extent will the funding available to States and Territories meet the demand for support required by the YPIRAC initiative?

In considering this, the evaluation shall have regard to:

(a) *availability of suitable housing;*

(b) *planning and development;*

(c) *developing system capacity;*

(d) *capital works;*

(e) *staff maintenance; and*

(f) *recruitment of skilled staff.*

1.3 Methodology

The methodology for this review included the following:

1.3.1 Review of data and documentation

A review of available program and reporting data to provide a baseline profile of activity and implementation across the jurisdictions. This Review drew on Program plans and administrative reporting for each of the jurisdictions, including their aims, objectives, performance targets and progress, implementation issues and functional needs assessment and other program delivery guidelines. It also drew on routine monitoring and performance reporting data already collected by respective jurisdictions and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

1.3.2 Literature review

In parallel with the data review above, Urbis conducted a limited literature review of relevant research and evaluation regarding comparable approaches to accommodation and support programs for young people with disability. The review aimed to identify key issues and criteria to refine the review approach.

1.3.3 Stakeholder interviews

The key stakeholders in this process were the relevant Program managers from respective Commonwealth, State and Territory Governments supporting this COAG initiative. In-depth telephone interviews with State/Territory officers to discuss responses to questions in the discussion guide was undertaken. It should be noted that any broader stakeholder consultation was not part of the scope of this evaluation.

1.3.4 Reports

This final report addresses the key evaluation questions, includes an assessment of findings, and reflects feedback provided by FaHCSIA and State and Territory Governments on draft reports.

1.4 Structure of this report

The structure of this report is as follows:

- Chapter two briefly outlines the nature of the Bilateral Agreements negotiated with each of the State and Territories to support the implementation of the Program.

- Chapter three details the performance of individual jurisdictions in relation to the targets established against the Program Objectives (POs). This includes analysis of reports provided by AIHW, the jurisdictional bi-monthly data reports and Implementation Progress Reports for the 2006/07 and 2007/08 periods.

- Chapter four provides analysis and discussion of the Program strengths and challenges based on the data provided by each jurisdiction and the targeted literature review which was undertaken for the project.

- Chapter five presents the findings and conclusions of the Mid-term Review and provides the rationale for a series of recommendations.

2 Nature of Bilateral Agreements

The Australian Government negotiated independent Bilateral Agreements with all Australian States and Territories to support the funding, implementation and progress monitoring of the YPIRAC Program in each location in relation to the YPIRAC Program.

The Bilateral Agreements were signed by the respective parties over the period August 2006 to January 2007.

While at a Program level, all Bilateral Agreements reflect the three POs, the targets and funding levels were individually negotiated and aim to reflect the various needs and demographic characteristics of each location.

2.1 Content of Bilateral Agreements

The Bilateral Agreements include several components:

- A letter of introduction from each jurisdiction.

- Information in the Bilateral Agreement that pertained to all jurisdictions.

- Schedule 1 of the Bilateral Agreement, which contained the evaluation and performance reporting framework.

- Schedule 2 of the Agreement, which contained financial arrangements.

- Schedule 3 of the Agreement, which contained the program of implementation for each jurisdiction.

Schedule 3 of the Bilateral Agreement contained the most useful information in relation to progress monitoring. This information includes performance targets, projected expenditure and detailed project plans for each jurisdiction. The project plans outline key activity areas, timelines, strategies, milestones and targets over the five-year Program timeline.

While the structure and content of all project plans are very similar:

- The Northern Territory, Victoria and Western Australia have all used the same template in the development of their project plan. A sample of the year one template is presented in Table 1.

- The structure used in the New South Wales and Tasmanian project plans differs only slightly from the template used by the above mentioned jurisdictions, specifically in their inclusion of some additional *activities.*

- The Australian Capital Territory, Queensland and South Australian project plans are based on the same template but outlined different *activities* to those of the other jurisdictions.

There was some commonality in the areas of activity to be undertaken during the initial implementation of the Program as outlined in the Bilateral Agreements, these included:

- Development of Program framework, guidelines, tools and data.

- Contact with YPIRAC and client group via the development of a communication strategy or activities.

- Establishment of governance arrangements such as working groups.

- Development of protocols with Aged Care Assessment Teams (ACATs).

- Assessment of the YPIRAC Program client group and their levels of needs.

- Provision of advocacy and support to the YPIRAC Program client group.

As will be discussed in the following chapter, the main difference in the initial two years of Program implementation across jurisdictions was the different emphasis on each of the POs.

Table 1 – Year one sample project plan template as used by a number of jurisdictions

Activity	Start date	End date	Strategies for success	Milestones	Targets	PO 1	PO2	PO3
Assessment								
Negotiating long term care options								
Provision of individual support/advocacy as part of determining option to move								
Provision of new care options								
Managing the ongoing care in new or existing arrangements								
Developing and establishing new service and care options								
Development of tools for assessing people at risk of protocols with ACATs								

2.1.1 Funding

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

Each individual Bilateral Agreement outlines a commitment to Program funding based on the number of YPIRAC clients in each jurisdiction and the activities that will be undertaken. Table 2 provides a summary of the Australian Government funding commitment to each jurisdiction.

Table 2 – Australian Government five-year funding allocations

New South Wales	Victoria	South Australia	Queensland	Western Australia	Tasmania	Northern Territory	Australian Capital Territory
$40,638,871	$30,126,251	$9,202,265	$23,866,328	$12,108,871	$2,900,649	$1,215,057	$1,941,708

2.1.2 National Evaluation and Performance Framework

The Bilateral Agreements outline a commitment to develop a National Evaluation and Performance Framework to support the monitoring of the Program at a national level.

As will be discussed in the following chapter, the AIHW was engaged to develop the YPIRAC National Minimum Data Set (NMDS) which has become an integral part of the ongoing monitoring of the Program nationally.

Other reporting activities required of jurisdictions as part of the evaluation framework include:

- Jurisdictional bi-monthly reporting
- Jurisdictional implementation plan progress reports
- Financial Acquittals.

2.2 Flexibility of Program across jurisdictions

As will be discussed in forthcoming chapters of this report, the flexibility afforded to each jurisdiction in developing and implementing the Program has been a positive factor in contextualising the Program to local requirements.

The review of all individual Bilateral Agreements however has highlighted a number of challenges for the Mid-Term Review and for articulating Program level achievements that can be attributed to the flexibility afforded to each jurisdiction, namely:

- An initial lack of commonality in defining the target group 'at risk' of admission to RAC.

- Program commencement at different times across different jurisdictions, with some jurisdictions commencing six months after others.

- Variation in the emphasis/focus on the three objectives based on jurisdiction-specific policy priorities and local circumstances.

- Delays in establishing a national data collection processes through the NMDS, resulted in inconsistent data collected for the 2006/07 period across individual jurisdictions.

- The Mid-Term Review has focused on the first two years of implementation.

2.3   Assumptions of Bilateral Agreements

The Bilateral Agreements have been an important tool to secure a joint funding commitment between the Australian Government and each State and Territory Government to achieve the YPIRAC Program objectives.

The agreements form the basis to the YPIRAC Program, both within individual jurisdictions, and nationally through the National Performance Monitoring, Evaluation and Reporting Framework.

The analysis presented in this report has therefore considered not only the content of the Bilateral Agreements, but the complex environment in which they were developed. Given the limited information available to the Australian Government, and State and Territory Governments regarding the YPIRAC target group, a number of assumptions were made at the Programs inception.

These assumptions were:

▪   The overall net reduction in the number of YPIRAC that will be achieved and at what stages this will occur in the five year Program cycle.

▪   The capacity of jurisdictions to influence the net number of YPIRAC through this Program.

▪   The levels of funding that will be required to achieve targets under each of the POs.

▪   The number of clients who will choose to participate in the Program and their perception of how well the Program meets their needs.

▪   The capacity of the community-sector to deliver services to younger people, often with high levels of disability.

Not withstanding the important role of the Bilateral Agreements in reaching national consensus and prioritising a response to YPIRAC, these early assumptions have shaped and impacted on the implementation of the Program across all jurisdictions. Subsequent chapters in this report will give detailed consideration to the impact of these assumptions on Program implementation to date, and in this context, one of the key evaluation questions for this review – *were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?*

3 Program Reporting and Data Collection

The ongoing progress monitoring of the YPIRAC Program is supported by the YPIRAC National Performance Monitoring, Evaluation and Reporting Framework.

The Framework outlines agreed performance indicators and data sources for measuring the effectiveness, efficiency and appropriateness, in meeting each of the Program objectives across jurisdictions.

Performance reporting is drawn from a number of sources, including:

- The YPIRAC Program (NMDS)

- Jurisdictional bi-monthly reporting

- Jurisdictional implementation plan progress reports

- Financial acquittals.

In June 2007 FaHCSIA engaged the AIHW to establish the YPIRAC Program NMDS. As part of this, the AIHW has submitted two reports outlining the findings of the analysis of the YPIRAC Program NMDS in 2006/07 and 2007/08.

In addition to interviews with jurisdictional representatives and the circulation of supplementary questions, this Mid-Term Review has been informed by the AIHW NMDS reports, the jurisdictional bi-monthly reporting and the progress reports.

This chapter provides a summary of national program and jurisdictional data extracted from the AIHW NMDS reports and jurisdictional bi-monthly reporting and progress reports.

3.1 AIHW NMDS reports

In developing the NMDS a trial period was established during the 2006/07 period allowing jurisdictions to comment on the NMDS.

A number of issues were identified during the trial period, which required changes to data definitions and categories in the 2007/08 period, including:

- Refining the definitions of 'YPIRAC service user' and 'YPIRAC assessment'

- The addition of 'YPIRAC client monitoring' as a service type

- Deletion of a number of redundant items in relation to service use, including service users' support needs and reasons why alternative accommodation was not offered

These changes, in addition to normal teething issues in the frequency and quality of data collected, has made the comparison between 2006/07 and 2007/08 NMDS difficult.

For the purpose of providing a summary snapshot of the YPIRAC Program national achievements to date, and client group characteristics, the AIHW 2007/08 report has been used.

3.1.1 Overall achievements as reported by the AIHW 2007/08 Report

As reported in the AIHW 2007-08 NMDS report, a total of 580 people received services funded by the YPIRAC Program during the 2007–08 period.

Of the 580 service users:

- 579 were offered one or more of YPIRAC assessment, individual care planning and client monitoring during the reporting period. There were 578 service users who accepted these offers and 577 who received a service under the Program.

- Around half (51%) had agreed to move from a RAC setting to alternative accommodation.

- 22% were considered 'at risk' of entry to RAC.

- 23% of service users were to remain in or enter RAC, while accessing additional support services.

- 2.2% were to remain in a RAC facility without additional services.

- 2.1% of YPIRAC service users had a target group that was not stated/unknown.

The following table from the AIHW 2007-08 NMDS analysis provides a snapshot of YPIRAC service users, age groups and target groups by jurisdiction for the 2007-08 period. Of the 580 services users:

- Victoria has the largest number of clients who have agreed or have been moved from RAC to alternative YPIRAC funded accommodation and support (99 people), followed by New South Wales (94 people)

- Queensland has the largest number of clients who have been identified as being at risk of entry into RAC (49 people), followed by Victoria (24 people) and South Australia (21 people)

- New South Wales has the largest number of YPIRAC who remain in, or enter RAC, with additional YPIRAC Program support (56 people), followed by Victoria (39 people)

Table 3 – YPIRAC service users, age group and target group by State/Territory 2007-08

| | State/Territory | | | | | | | | Total | |
	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	No.	%
<50 years										
Group 1	83	82	34	20	18	3	2	3	245	42.2
Group 2	2	20	38	13	20	3	5	4	105	18.1
Group 3	46	36	9	—	7	8	—	3	109	18.8
Group 4	4	—	2	1	5	—	—	—	12	2.1
Not stated	—	12	—	—	—	—	—	—	12	2.1
Total <50 years	135	150	83	34	50	14	7	10	483	83.3
50–64 years										
Group 1	11	17	6	6	6	3	2	—	51	8.8
Group 2	—	4	11	2	1	—	2	—	20	3.4
Group 3	10	3	6	2	1	—	2	1	25	4.3
Group 4	1	—	—	—	—	—	—	—	1	0.2
Not stated	—	—	—	—	—	—	—	—	—	—
Total 50–64 years	22	24	23	10	8	3	6	1	97	16.7
All service users										
Group 1	94	99	40	26	24	6	4	3	296	51.0
Group 2	2	24	49	15	21	3	7	4	125	21.6
Group 3	56	39	15	2	8	8	2	4	134	23.1
Group 4	5	—	2	1	5	—	—	—	13	2.2
Not stated	—	12	—	—	—	—	—	—	12	2.1
Total	**157**	**174**	**106**	**44**	**58**	**17**	**13**	**11**	**580**	**100.0**

Note: YPIRAC target groups:

Group 1 Agreed to or has moved from residential aged care to alternative YPIRAC funded accommodation and support

Group 2 Deemed 'at risk' of entry into residential aged care

Group 3 Remain in or enter residential aged care with additional disability support services

Group 4 Remain in or enter residential aged care without additional disability support services.

Source: AIHW 2009, p 6

3.1.2   Characteristics of service users

Of the total number of YPIRAC service users in 2007-08,

- 83% were aged under 50, reflecting the Program's priority focus at a national level.

- Those aged 40 to 49 years accounted for more than half of all service users (54%).

- Around 14% of all male service users were aged less than 30 years, compared with 5.8% of females.

- 42 were of Aboriginal and/or Torres Strait Islander origin (7.2%). The proportion of Indigenous service users varied across State/Territory jurisdictions, from 73% of all YPIRAC service users in the Northern Territory, to zero in Tasmania.

Around half (53.1%) of YPIRAC Program clients had more than one significant disability. The primary disability groups of YPIRAC service users in 2007-08 were:

- Acquired Brain Injury (ABI) (46.4%)

- Neurological (26.7%)

- Physical (16.6%).

3.1.3   Types of services accessed by YPIRAC Program clients

Of the 580 service users:

- 30% received accommodation support. This includes the provision of services to enable a client to remain in their existing accommodation or to move to more appropriate accommodation.

- 26% received community access support. This includes services designed to provide opportunities for clients to gain and use their abilities to maximise their social independence, such as self-help and social skills programs, cooking classes and recreational activities (e.g. trips to art galleries).

- 23% accessed community support services. This includes services needed for a client to live in a community setting such as therapy, behavioural/specialist intervention and counselling.

- 2.8% received respite services. This includes the provision of support to allow for short term breaks for families and other voluntary care givers and can be delivered in the client's own home, or in respite homes or centres. Crisis respite can also be provided.

- 99.7% accessed other services. This includes advocacy, information and alternative forms of communication, YPIRAC assessments, YPIRAC client monitoring.

The most commonly accessed community support services were:

- Therapy support (16%)

- Case management, local co-ordination and development (12%).

 Within the community access group, the service type most commonly received were:

- Other community access (18%)

- Learning and life skills development (7.8%).

Transport services were accessed by 14.5% of service users.

3.2 Summary of jurisdictional program implementation as reported in the 2006/07 and 2007/08 progress reports

This section provides a summary of the activities and progress towards targets by each jurisdiction for the initial two years of Program implementation, 2006/07 and 2007/08.

Information has been collated from jurisdiction progress reports provided in August 2007 and August/September 2008.

The Implementation Progress Reports written by the various State and Territory jurisdictions for 2006-2007 were presented in a number of formats, ranging from detailed discussions to summaries and tables. One of the challenges in presenting this information is the fact that there were no specific reporting requirements, thus allowing States and Territories to forge their own direction in their Implementation Plans. The documents written by the various jurisdictions generally provided a summary of their progress and achievements with regard to young people in RAC. Some jurisdictions addressed key issues such as governance, communication strategies, planning and assessment, service development, enhancement within RAC and diversion whilst others focused on specific State and Territory agreed outputs.

As a consequence of the difference between the Implementation Plan Progress Reports across the States and Territories for 2006-2007, the Implementation Plan Progress Reports for 2007-2008 were more streamlined and based on a standard template. These documents provided a detailed analysis of the outcomes achieved for young people with disability residing in or at risk of entering RAC.

In general, the Implementation Plan Progress Reports of 2007-2008 demonstrated that each jurisdiction is committed to ensuring sustainable and long-term options are developed to ensure younger people living in or at risk of entering RAC have appropriate accommodation and support options in the community.

Key milestones across the States and Territories in 2007-2008 included progress against projected targets; assessment processes in place; assessments undertaken, and the number of people assisted across the three objectives of the program (i.e. number of care plans), activities relating to the transition to new care options and the development of new and long term care options.

Furthermore, there has been successful management of:

- Ongoing care in new or existing arrangements.

- The development and progress of capital works.

- Development of protocols with ACATs and other agencies.

- Application of quality assurance measures and activities associated with measuring quality of life for the target group.

- Activities associated with the development of responses to people of diverse cultural backgrounds and Aboriginal Torres Strait Islanders, and communication or consultation strategies.

3.2.1 Implementation tools

Overall, all jurisdictions have undertaken significant work to ensure measures to support implementation processes, such as guidelines and assessment tools, are in place for the Program.

Overall, activities and processes undertaken to support Program implementation by States and Territories can be best categorised as follows:

- Stakeholder engagement - including consultation/focus groups with peak organisations and service providers, engagement with clients and advocates, and the development of communication strategies.

- Development of governance structures – including the use of existing internal working groups or the establishment of expert working groups or steering committees.

- Development of data collection systems – involving the establishment of processes to collect required information and the use of tools such as quality of life indicators to assess progress.

- Assessment/in-take processes – including the development of assessment processes to identify clients 'at risk' of entering residential aged care; frameworks to identify priority clients; the development of a logic for the allocation of Program funding across the jurisdiction, and the development of protocols/arrangements with ACATs or ACAS (Aged Care Assessment Service) to ensure consistency in the identification and/or assessment of clients.

- Identification and engagement of service providers to deliver the Program – collaboration with other agencies such as housing or health departments to support the delivery of services or development of capital works, and expressions of interest/tendering process to engage new service providers to deliver services and build capital.

3.3 Australian Capital Territory

The Australian Capital Territory YPIRAC Program experience has been shaped by:

- The comparatively small number of YPIRAC Program clients and targets (n=12).

- The fact that due to its geographical size, Program clients are likely to be located in centralised locations, in reasonable proximity to each other, and existing service structures.

As per the summary information presented below, the first two years of the YPIRAC Program in the Australian Capital Territory focused on the development of Program architecture, processes and key networks to support future Program implementation. This included negotiations with ACATs regarding client assessment and referral Protocols.

Table 4 – Australian Capital Territory: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Australian Capital Territory Program highlights for year one (06/07)…	- Communication activities implemented, including: Completion of communication strategy, contacted all YPIRAC under 55 years. - Planning and assessment activities including: Establishment of an advisory committee, development of transition plans, eligibility criteria, priority for service criteria, advocacy support, and processes to review decisions and privacy and confidentiality. - PO2 activities: Initial negotiations to develop a YPIRAC-ACT and ACAT Protocol to ensure that younger people at risk of entry into RAC are assessed by the YPIRAC Program.
Australian Capital Territory highlights for year two (07/08)…	- Continued planning and assessment activities including: Finalised assessment tool for clients to record their desires regarding the Program. - Continued PO1 activities: Tender for capital works conducted and architect appointed. - Continued PO2 activities: Undertook an application and assessment process including defining the eligibility criteria, prioritising of applicants, assisted with planning and linking to appropriate services, and allocated resources above the required targets for PO2. - Continued PO3 activities: Undertook an application process, supported and assisted individuals with planning and linking to appropriate services, and allocated resources.

3.4 Progress towards Program targets

When considering the progress towards Program targets in the Australian Capital Territory, it is important to note that the overall five-year target was 12 people – four in each PO.

It should be noted that due to the small number of people with a disability (who meet the YPIRAC eligibility) under 50 years, the priority target group in the ACT includes people 55 years and under.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Australian Capital Territory	0	1	0	7	0	5

3.5   Queensland

As per the summary information presented below, the first two years of the YPIRAC Program in Queensland focused significantly on the development of Program architecture, processes and key networks to support future Program implementation.

Early investment in communication activities with Program stakeholders, identification of Program partners and the establishment of planning and assessment processes provided a strong foundation for the Program implementation, particularly:

▪ The development of a suite of client assessment tools and aid in selecting accommodation and support options:

– *Preliminary Assessment Skills and Functioning Tool Report -* focus on client history, medical history, physical functioning, and cognitive skills.

– *Options Planning Report* focus on client and family identifying daily client support requirements.

– *Client Profile Tool* – focus on identifying client-focussed goals as discussed with client, family and networks.

– *Risk Assessment Tool* – focus on identifying levels of client transitioning within the community. This helps service providers assess the resource intensiveness/staffing demands that will be required to meet client needs.

– *Person Centred Mapping Tool* - focus on indentifying the client's desires and aspirations, important relationships and places, likes and dislikes, and the choices they would like to make.

▪ Development of *Younger People with Disability in RAC Eligibility and Assessment Policy* and, *Younger People with Disability in RAC Prioritisation Policy* and criteria for identifying people 'at risk' of entry into RAC.

The Program initial focus has been on the development of strategic partnerships with non-government organisations to build alternative accommodation options for Program clients, and identify suitable community-based service providers to provide support clients living outside of RAC.

Table 5 – Queensland: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Queensland Program highlights for year one (06/07)…	▪ Communication activities implemented, including: YPIRAC Program information package and invitations sent to 320 YPIRAC or younger people at risk of entry into RAC. ▪ Planning and assessment activities including: Funding provided to the Brain Injury Association of Queensland to establish the *Assessment and Options Planning Service* and conduct 200 assessments over two years. The assessment of YPIRAC Program clients is supported by a suite of various tools and aims to determine the client's disability support and health care needs and identify suitable Program options.

	- PO1 Activities: Allocation of recurrent and non-recurrent funding to Wesley Mission Brisbane and Youngcare to develop a 16 bed apartment complex for YPIRAC Program clients who have high or complex. This component of the Program is called the *Integrated Living Model*. - PO2 Activities: Development and tendering for service providers to implement three support models - *Living with Family and Network Supports Model, Living Independently Model, and Shared Supports Model*. The *Living with Family and Network Supports Model* represent a collaborative approach between the person's carers and formal support services to develop sustainable care arrangements.
Queensland highlights for year two (07/08)…	- Continued communication activities: YPIRAC Program information package and information sent to target group who had not responded to initial invitation. Contact was also made with 17 YPIRAC who had been admitted into RAC since July 2006. Direct correspondence was also sent to Directors of Nursing in RAC where clients had not responded to initial correspondence seeking their support in promoting the Program. Follow up phone calls were also made. - Continued planning and assessment activities: Development of additional tool - *Person Centred Mapping Tool* which indentifies the clients needs, desires and aspirations, important relationships and places, likes and dislikes, and the choices they would like to make. Finalisation of guidelines for the assessment of people considered to be 'at risk' of entry into RAC. Discussion with Queensland Health regarding the development of a Protocol with ACATs to avoid the admission of younger people into RAC prior to the client being considered by the YPIRAC Program. - Continued PO1 activities: Operation of two accommodation and support options commenced. Negotiations also commenced with two additional non-government organisations for the construction of accommodation options. - Continued PO2 activities: Service providers were selected through a tender process to deliver support under *Living with Family and Network Supports Model, Living Independently Model, and Shared Supports Model*.

3.5.1 Progress towards Program targets

The table below provides a quantitative summary of the Queensland YPIRAC Program progress towards meeting its targets. Data reflects the Program-focus to date on PO1 and PO2. Further achievements in PO1 are expected as construction of accommodation options is completed.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Queensland	35-43	25	36-44	35	6-12	0

3.6   New South Wales

As per the summary information presented below, the first two years of the YPIRAC Program in New South Wales focused on the development of Program architecture, processes and key networks to support future Program implementation.

Early investment in communication activities with Program stakeholders, identification of Program partners and the establishment of planning and assessment processes provided a strong foundation for the Program implementation.

During the initial two years of the Program New South Wales undertook various procurement processes to identify service providers to assist in Program activities under PO1 and PO3. In relation to PO2, *Enable NSW* was provided funding to procure, supply and maintain equipment for at least 50 YPIRAC Program clients.

Table 6 – New South Wales: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

New South Wales Program highlights for year one (06/07)…	- Communication activities implemented, including: Communication strategy finalised, Program information line established, application packs sent to all YPIRAC under 50 years, and follow-up of non-respondents. - Planning and assessment activities including: Program staff recruited, expert working group and internal reference group convened, Program policies and guidelines developed including *Complaints & Appeals Guidelines* and *Assessment Package and Support Planning Procedures and Guidelines*, data base for management of client records established, assessment methodology and prioritisation tools developed, and training of assessors. - PO1 activities: Commenced procurement of services to establish three new supported accommodation places in the Hunter Region, and the provision of ten accommodation places in the Sydney metropolitan area. - PO2 activities: *YPIRAC Program – ACAT Protocol* progressed to ensure at risk client group is identified as early as possible and referred to YPIRAC Program for assessment. - PO3 activities: Commenced procurement of services to purchase six specialist disability support packages for people remaining in RAC.
New South Wales highlights for year two (07/08)…	- Continued communication activities: Further application packs distributed to Program clients, information on advocacy services and Program fact sheets distributed. - Continued PO1 activities: Completion of four bedroom house and transition of clients to this new accommodation. Additional procurement process will be undertaken in September-December 2008 with an expected 100 new accommodation places created. - Continued PO2 activities: Funding provided to *Enable NSW* to procure, supply and maintain equipment for at least 50 applicants. - Continued PO3 activities: Procurement process completed for the *In-reach packages* to enhance specialist service delivery to YPIRAC. Funding provided for 50 *In-reach packages* by four service providers.

3.6.1   Progress towards Program targets

As will be discussed in the following sections of the report, there have been some initial delays in New South Wales completing capital works to relocate Program clients (PO1) and in establishing strategic partnerships to divert clients from entering RAC. (PO2). With the completion of procurement processes as part of PO1, and the appointment of *Enable NSW* (PO2), it is expected that performance data for the January 2009 – June 2009 period will indicate significant progress in the implementation of PO1 and PO2.

In considering the New South Wales performance over the initial two years of the Program it is important to note that the Bilateral Agreement was not formally accepted until December 2006. Effectively the reporting period 2006/07 only represents six months of Program activity.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
New South Wales	44-88	2	19-36	2	65-100	199

3.7   Northern Territory

The Northern Territory YPIRAC Program experience has been shaped by:

- The comparatively small number of YPIRAC Program clients.

- The fact that many of these clients are in various regional areas, making the provision of YPIRAC Program services highly decentralised.

As per the summary information presented below, the first year of the YPIRAC Program in the Northern Territory focused on recruiting YPIRAC Program staff, developing the capacity of the sector, for example through the training of ACATs, and conducting assessments of all YPIRAC clients.

The rapid assessment of all clients within the first year of the Program has allowed the Program to be implemented in a very targeted and resource effective manner. For example, the initial focus in Darwin was only in relation to home modifications (PO2), given that the only YPIRAC Program client in Darwin preferred to live in the family home. The number of clients (n=3) in Alice Springs on the other hand who preferred to relocate to a purpose-modified facility, supported the modification of a group home for the specific needs of the YPIRAC Program target group.

Table 7 – Northern Territory: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Northern Territory Program highlights for year one (06/07)…	- Communication activities implemented, including: Contact was made with all YPIRAC Program target group and consent obtained for assessment as part of the Program. Partnerships with key stakeholders such as the Aged Care Advocate and Adult Guardians at the local level. - Planning and assessment activities including: Guidelines and Protocols for the Northern Territory YPIRAC Program were finalised. Recruitment of staff to conduct individual assessments of YPIRAC Program clients was completed, and all assessments were conducted. Reports were prepared on clients based on a *Comprehensive Behavioural Analysis*. Data collection tools to assess Program impacts were also developed. - PO1 activities: Negotiated with Territory Housing for the modification of one alternative group home for YPIRAC Program. - PO2 activities: Developed assessment tools to identify younger people at risk of entry into RAC. The Northern Territory ACAT Manual was updated to reflect the new tools and processes for diverting younger people from entry into RAC, and training was provided to ACATs. Tenders for alternative care options were made available to community sector. - PO3 activities: Tenders for alternative care options were made available to community sector.
Northern Territory Program highlights for year two (07/08)…	- Continued planning and assessment activities: Finalised a range of tools to assess client needs, including *Disability assessment*, *Disability Report*, *Individual Support Plan (immediate needs)* and, *Disability Support Plan (long term)*. - Continued PO1 activities: Group home established in Alice Springs. - Continued PO2 activities: One client provided funding to return to family home with specialist equipment, home modifications, and additional support services. - PO3 activities: Services funded for clients in Tennant Creek and Katherine

	RAC

3.7.1 Progress towards Program targets

The table below provides a quantitative summary of the Northern Territory YPIRAC Program progress towards meeting its targets. PO1 and PO2 targets for the period ending June 2009 were met by December 2008, and PO3 targets are likely to be met within the specific timeframe.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Northern Territory	2-3	2	1	6	4	3

3.8   South Australia

The South Australian YPIRAC Program, *Young People in Nursing Homes Project*, achieved significant outcomes in its initial two-years of implementation.

Through the development of a comprehensive Program framework in the very early stages, clear guidance was provided in relation to the assessment of Program clients, eligibility criteria and processes to implement the Program under each PO. This allowed for the rapid access to Program clients, stakeholders and implementation of strategies.

While the majority of jurisdictions focused their initial efforts on different POs, the South Australian Program has managed to achieve significant outputs across all three POs.

Table 8 – South Australia: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

South Australia Program highlights for year one (06/07)…	- Communication activities implemented, including: Initial contact made with YPIRAC client group, consumer consultation and workshops. - Planning and assessment activities including: Steering committee convened, Program framework developed - including eligibility criteria, and client assessment process and tools, including *My Life-My Plan.* . - PO1 activities: Clients relocated to more appropriate accommodation as per year one targets. Commenced development of six to seven cluster sites to accommodate up to 50 people and 13 individual accommodation options in regional/remote areas. - PO2 activities: Clients diverted to more appropriate accommodation exceeding year one targets. Development of process to purchase, maintain and distribute equipment to facilitate relocation to home or other community based accommodation. - PO3 activities: Clients provided enhancement packages as per year one targets.
South Australia Program highlights for year two (07/08)…	- Continued planning and assessment activities: Communication plan developed and implemented. - Continued PO1 activities: Two cluster sites to accommodate seven clients have been completed. Construction of remaining cluster sites commenced, completion due July 2009. Working towards acquiring additional land for development of new cluster sites. - Continued PO2 activities. - Continued PO3 activities.

3.8.1   Progress towards Program targets

The table below provides a quantitative summary of the South Australian YPIRAC Program progress towards meeting its targets. As previously mentioned, significant progress has been made towards achieving targets across all three POs.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
South Australia	24	17	14	19	17	8

3.9   Tasmania

The Tasmanian YPIRAC Program experience has been shaped by:

- The comparatively small number of initial YPIRAC Program clients and targets under 50 years (n=14).

- The fact that many of these clients are in various regional areas, making the provision of YPIRAC Program services decentralised.

While the initial two years of implementation focused on the development of Program frameworks, guidelines and processes, given the small number of the YPIRAC Program target group, initial assessments of all clients were completed.

It is worth noting that given the Program has not scheduled the development of alternative accommodation (PO1) until year three, clients were more likely to be referred for enhancements (PO3) until the facilities are completed and they are relocated.

Table 9 –Tasmania: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Tasmanian Program highlights for year one (06/07)…	- Communication strategy implemented, including: Development and implementation of communication strategy. Contacted all YPIRAC Program clients under 50 years, their families or advocates.
	- Planning and assessment activities including: recruitment of Program staff, purchased assessment tool developed by the Summer Foundation for Victoria, majority of assessments completed, and reference network established.
	- PO1 activities: Commenced to plan for a capital development program to be implemented in year three of the Program. Held initial consultations with service providers regarding the most appropriate accommodation models.
	- PO2 activities: Development of Protocol with ACATs to assist in the identification of younger people at risk of entering RAC.
	- PO3 activities: Provided services to a number (three) of YPIRAC. These included Community Access services such as day programs, specialised equipment and access to health professionals.
Tasmanian Program highlights for year two (07/08)…	- Continued communication activities: Accommodation forum was held to discuss the criteria for the development of capital –this included attendance by some of the proposed residents, disability service providers and the Program's steering committee. Program Information sessions were also held with peak bodies, and fact sheets produced for Program staff and clients.
	- Continued planning and assessment activities: Staff attended training sessions regarding transition planning, key Program staff completing training at TAFE regarding transition planning.
	- Continued PO1 activities: A site has been selected for the new accommodation service and an architect appointed.
	- Continued PO2 activities: An *at risk scale* for entry to RAC was developed in conjunctions with RAC to assist in the prioritisation of clients.
	- Continued PO3 activities.

3.9.1 Progress towards Program targets

The table below provides a quantitative summary of the Tasmania YPIRAC Program progress towards meeting its targets.

In considering the Tasmanian performance over the initial two years of the Program it is important to note that the Bilateral Agreement was not formally accepted until December 2006, with recruitment of a Program manager completed in January 2007.

Effectively the reporting period 2006/07 only represents six months of Program activity.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Tasmania	0	1	3	3	16	15

3.10   Victoria

As per the summary information presented below, the first two years of the YPIRAC Program in Victoria, *my future my choice,* focused significantly on the development of Program architecture, processes and key networks to support future Program implementation. The delivery of planning and assessment, alternative living options and enhancement supports also commenced during this period.

Early investment in communication activities with Program stakeholders, identification of Program partners and the establishment of planning and assessment processes provided a strong foundation for the Program implementation.

To facilitate the planning and assessment process:

- Eight planning organisations have been engaged to work with YPIRAC Program clients and their families in the development of their individual plans across the State.

- An independent advocacy service has been established (Action for Community Living) to provide support to Program clients unable to communicate their preferences or with no family/support network to represent them.

In addition, the Program has invested in early communication with ACAS and the acute and health and rehabilitation sector to ensure coordination of stakeholders across the continuum of entry into RAC and short and long term care. As part of this a diversionary strategy (PO2) has been developed to ensure the efficient diversion of younger people at risk of entry into RAC. This includes criteria for defining and assessing clients 'at risk' of entry into RAC.

Table 10 – Victoria: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Victorian Program highlights for year one (06/07)…	- Communication strategy implemented, including: Communication with all YPIRAC, their families, RAC services, peak bodies and community service organisations, newsletters, and establishment of Program hotline, website and email address. - Planning and assessment activities including: Planning and assessment framework developed by the Summer Foundation, all Victorian YPIRAC offered opportunity to participate in Program planning and assessment, independent advocacy service established (Action for Community Living), central stakeholder panel established to consider individual plans and allocate resources, complaints process established. - PO1 activities: Service providers have been identified to provide innovative support services for 46 people with moderate to high care needs. Commenced development of a new facility-based service for 10 people with high-level support needs and associated clinical care needs to be located in the inner urban area, and the expansion of a neurological service to provide for additional three places - PO2 activities: Diversionary strategy developed to minimise the number of new admissions of younger people to RAC, criteria to identify 'at risk' Program population of entry into RAC, enhanced communication between Program and ACAS, and with acute and health and rehabilitation sector.

Victorian Program highlights for year two (07/08)…	- Continued communication activities: Summary of Program planning and assessment process was published - *Younger people in residential aged care, Support needs, preferences and future directions* report. - Continued planning and assessment activities: Assessments completed for the majority of Program clients who had consented to Program participation, regional process established to facilitate direct contact and information dissemination, process finalised for verification of final individual plans (including review of proposed costing, implementation, monitor and review). - Continued PO1 activities: Funding allocated for the development of seven new services for 46 people, with expected completion by December 2010. The first of these services opened in February 2008. Planning is underway for a further 47 accommodation support places - Continued PO2 activities. - PO3 activities: Focus on purchasing additional disability supports to help the Program client meet their personal goals and improve the quality of their life. Outcomes for these clients include increased ability to participate in social and recreational activities, enhanced opportunities to develop and/or maintain family and friendship networks, and the purchase of items such as attendant care support, equipment and therapy.

3.10.1 Progress towards Program targets

The table below provides a quantitative summary of the Victorian YPIRAC Program progress towards meeting its targets. In relation to the underperformance of PO1, it is important to note that seven new services to accommodate up to 46 people are expected to be completed by December 2010.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Victoria	71	19	15	41	20	119

3.11   Western Australia

The Western Australian YPIRAC Program experience has been particularly unique due to a number of jurisdictional specific factors:

- The YPIRAC target group was known to the government and services/programs were already in place to support their needs. The *Combined Application Process (CAP)* tool for example, to assess younger people at risk of entry to RAC, had been in use for over seven years. This allowed for the Program to commence implementation comparatively quickly, particularly in supporting people as part of PO2. In this context, existing processes and arrangements with service providers were maximised and YPIRAC Program clients benefited from minimal delays in accessing services.

- Despite the Program establishing strategic partnerships with service providers to remodel existing capital for the YPIRAC Program in the first two years, delays have occurred due to the increased demand for building services resulting from the mining boom. Access to building contractors has therefore been limited.

Table 11 – Western Australia: Summary of YPIRAC Program highlights (2006/07 and 2007/08)

Western Australia Program highlights for year one (06/07)…	- Communication strategy implemented, including: Initial contact letters, Program information and Registration of Interest (RoI) information was forwarded to all known YPIRAC in Western Australia. Correspondence was also sent to the Chief Executive Officers and Directors of Nursing of relevant RAC facilities encouraging promotion of the YPIRAC Program. - Planning and assessment activities including: Initial interview and assessment process has been developed. In addition, an existing tool, the *CAP,* has been used to assess younger people 'at risk' of entry into RAC. The tool has been in operation in Western Australia for over seven years. 16 service providers expressed interest in providing services as part of the YPIRAC Program. - PO1 activities: One service provider was engaged to redevelop existing accommodation to support 10-15 YPIRAC Program clients. An additional redevelopment to accommodate 10-12 YPIRAC clients will commence once a suitable provider is identified. Both redevelopments are expected to be completed by years four and five of the Program. Initiated negotiations with the Western Australian Department of Housing to build fully accessible housing options, it is expected that a total of nine units will be remodelled for YPIRAC Program clients. - PO2 activities: Given the CAP tool was in use, PO2 has been the initial Program focus. Funding has been used to assist YPIRAC Program clients remain in their home. - PO3 activities: Initial identification of specialist services.

Western Australia Program highlights for year two (07/08)…	• Continued communication activities: All YPIRAC have been contacted and provided an opportunity to participate in the Program. Particularly targeted potential Aboriginal Program clients in the North West of Western Australia. Aboriginal Liaison Officers have been visiting regional and remote communities to discuss the Program.
	• Continued planning and assessment activities including: Planning process developed and ensures that key stakeholders are involved in the assessment of each individual to develop *care plans* are developed for each client. Development of Protocols with ACATs completed.
	• Continued PO1 activities: Three facilities are expected to be completed by 2008/09, of these, one will have a focus on Huntington's disease and one on ABI. Two additional accommodation facilities have been identified, and will be completed by 2010.
	• Continued PO2 activities.
	• Continued PO3 activities.

3.11.1   Progress towards Program targets

The table below provides a quantitative summary of the Western Australian YPIRAC Program progress towards meeting its targets. In relation to the underperformance of PO1, it is important to note the unique challenges presented by the shortage of building contractors. Given a number of facilities are well into construction, and the progression of arrangements with the Department of Housing to remodel existing accommodation for the needs of YPIRAC Program clients, it is likely that the PO1 targets will be achieved within the initial five-years of the Program.

Jurisdiction	Target to June 2009 - PO1	Achievement at December 2008 – PO1	Target to June 2009 - PO2	Achievement at December 2008 - PO2	Target to June 2009 - PO3	Achievement at December 2008 – PO3
Western Australia	12	3	18	16	24	11

3.12 Contextualising Program achievements to date

As noted in the summaries presented in this chapter, jurisdictions have accomplished a significant amount during the initial two years of Program implementation, particularly given that this Program represents the first nationally coordinated approach to respond to the needs of YPIRAC.

Many of the early Program achievements focused on the development of local processes and frameworks to support the implementation of the Program, and better understand the needs of the target group. This early investment has been an important step in ensuring a coordinated response to the complexity of the YPIRAC Program – which demands a jurisdictional response across the aged care, health, housing and community services sectors, both within government and the non-government sectors.

While much of the analysis presented in the forthcoming chapters has focused on answering key questions such as whether the net reduction targets will be achieved, the successful completion of these goals can be largely attributed to the early investment in establishing the required service and policy architecture across each jurisdiction.

3.12.1 Program funding

Given the importance of setting up the initial jurisdictional service and policy infrastructure, the majority of jurisdictions (n=6), will access 62 per cent of their Program funding only in the last two years of the Program (2009/10 and 2010/11).

The rationale for this funding structure reflects the early jurisdictional investment in understanding the needs of the client group, and responding to many of the early assumptions reflected in the Bilateral Agreements. This has been an important step in ensuring the future success of the Program.

In this context, while the analysis in forthcoming chapters considers whether the Program targets will be achieved within existing funding allocations, this Mid Term Review cannot address whether the funding available will be sufficient to meet the demand for support required by the YPIRAC target group for a number of reasons, namely:

- Analysis has focused only on 2006-07 and 2007-08 data.

- No itemised financial data in relation to the cost of providing services has been made available.

- Given only two years of implementation have taken place, it is too soon to assess the cost per client, and whether allocated amounts will be adequate. Jurisdictions have reported they will be able to meet targets within current funding allocations.

These are all important issues that will be better addressed in the five-year evaluation should access to sufficient itemised financial data be made available by jurisdictions.

4 Program implementation and outcomes – discussion

4.1 Overview

This chapter provides analysis and discussion of the Program strengths and challenges based on data provided by jurisdictions and the literature review undertaken for the project.

Central to the analysis is an understanding of the complexity of the interface between health, aged care, disability services, community services and housing in which the YPIRAC Program is based.

Overall, the Program has met an important and tangible need for many younger people with disability. It is expected that by the conclusion of the five year Program, the net reduction target of between 425-689 in the number of YPIRAC will have been achieved.

However, despite the Program meeting the target, a significant demand for services for YPIRAC will remain. This is particularly the case for clients with very high needs and for those in rural and remote locations.

Overall, the Program implementation to date has been successful in achieving a number of important outcomes:

• For clients and their families	It has provided genuine individualised alternatives to inappropriate RAC for younger people with disability in a flexible and tailored service environment.
• From a service delivery perspective	It has facilitated the development of partnerships by governments, across jurisdictions and with the non-government sector to enable the delivery of community-based care options or enhancement services to YPIRAC, and the development of purpose-built or modified facilities.
• From a policy perspective	It has set a benchmark for servicing arrangements in complex environments and collated critical data to inform the development and delivery of Programs targeting younger people with disability nationally and across individual jurisdictions.

4.2 The complexity of the YPIRAC Program

While the circumstances of YPIRAC had been previously known to governments and the service sector, this Program represents the first nationally coordinated attempt to respond to the complex needs of this highly vulnerable and neglected group.

The establishment of the Program included the development of:

- Program Objectives
- Bilateral Agreements
- Targets
- Action Plans
- Financial allocations.

These were based on the best evidence available at the commencement of the Program. A certain number of assumptions were made in relation to:

- The overall net reduction in the number of YPIRAC that will be achieved and at what stages of the five year Program cycle.

- The capacity of jurisdictions to influence the net number of YPIRAC through this Program.

- The levels of funding that will be required to achieve targets under each of the POs.

- The number of clients that will choose to participate in the Program and how well they perceive it to meet their needs.

- The capacity of the community-sector to deliver services to younger people often with high levels of disability and complex or associated health conditions.

Discussion in this chapter will explore the implications of these assumptions and their impact on the findings of the Mid-Term Review. This chapter explores the assumptions and application of the Bi-lateral Agreement, the strengths and challenges of the Program structure and design, and draws conclusions regarding the Program's current progress toward its stated objectives.

4.3   The Bilateral Agreements

The Bilateral Agreements reflect all the Program assumptions outlined above.

This Review has found that despite best efforts, a number of assumptions in the structure of the Bilateral Agreements had limited validity. Table 12 describes the key Program assumptions and the actual experience of jurisdictions.

Table 12 – Program assumptions, delivery and impacts on Program outcomes

Assumption	Program delivery	Impact on outcomes to date
The tasks and timelines involved in setting up the Program in each jurisdiction.	- Lack of sector-wide experience in supporting younger people with disabilities, particularly high need clients, in community settings. - Lack of accurate and timely information regarding clients. - Although time consuming, the importance of face-to-face contact with the clients and their families has been emphasised as important to program set up by jurisdictions.	- Delays in recruitment due to skill shortages. - Skill gaps remain in relation to supporting transition planning and responding to the changing health needs of clients, particularly those with degenerative conditions. - A time lag has been experienced between client assessment and service availability due to delays in service development.
The level of client need would be evenly split across the four levels of support – low, medium, high and very high	- The experience in most jurisdictions to date is that the majority of the YPIRAC target group have high or very high needs. - In Victoria this has been estimated as being as much as 75 per cent of the target group. Similarly, in 2005, it was estimated that of the Queensland YPIRAC population, 81.5 per cent have high care needs.	- Significant challenges are faced in finding appropriate support arrangements for clients with high support needs. - Increased cost in the provision of services limits the number of clients the Program can assist.

Assumption	Program delivery	Impact on outcomes to date
	▪ As expected, high care needs result in the need for service provision 24 hours a day, to assist people with showering, dressing, toileting, eating and mobility. ▪ For community based services, a range of equipment is needed to service the needs of high support needs clients. The Summer Foundation (2007) estimated that 52 per cent of the Victorian YPIRAC research sample utilised five or more items of specialised equipment.	
The cost of providing care for each client.	▪ South Australia for example has indicated that in its initial modelling the individual provision of services was budgeted at $80,000 on average per client. Given the unexpected number of high need clients the actual cost is $100,000-$120,000 per client. ▪ Queensland and Western Australia have also reported that to ensure cultural sensitivity in the delivery of the YPIRAC Program to Indigenous clients and their families, significant investments in travel to remote communities has been undertaken. Whilst this has been crucial in responding to cultural, linguistic and historical needs of Indigenous clients, the long travel distances between communities have resulted in increased Program costs.	▪ Tasmania and the ACT Program budgets were 're-phased' by negotiation with the Commonwealth Government to achieve a different allocation over the five years of the Program across each PO to better match Program objectives and targets. The overall allocation did not change. ▪ The Program will not be able to respond to the needs of all YPIRAC. Significant service demand will remain for the under 50 years target group, even when the Program meets its targets after five years. ▪ Issues of service-capacity will remain a challenge in the delivery of services to rural and remote clients.
The targets that will be achieved under each PO and at what stages.	▪ All jurisdictions experienced delays in commencing the Program as they developed procedures, guidelines and engaged stakeholders. ▪ Jurisdictions also experienced delays in developing or modifying facilities, and establishing service delivery arrangements with providers. ▪ Not all targets have been met to date.	▪ In most instances, overall targets will be met by year five but not within the specified milestone time frames for the early phase of the Program. ▪ Queensland and Tasmania renegotiated their targets across the five-year Program (although the overall number of people to be assisted did not change). ▪ Victoria and Western

Assumption	Program delivery	Impact on outcomes to date
		Australia indicated the possibility of renegotiating its targets.

4.3.1   Use of Bilateral Agreements

The use of Bilateral Agreements for the Program engages the relevant agencies across levels of government and jurisdictions. They are a necessary tool for these purposes. Bilateral Agreements do not necessarily provide jurisdictions with the flexibility to easily change targets and milestones under each PO as the Program evolves because of the manner in which they require renegotiation with relevant Ministers to afford changes.

However, any potential negative impacts on Program flexibility through the use of Bilateral Agreements have been mitigated, through good management by the Commonwealth by:

- The flexible approach of FaHCSIA in renegotiating targets and the timing of funding to better reflect the actual challenges in Program implementation. This has been a particularly important component of the Program to date.

- The five-year timeframe for the initiative which allows jurisdictions to 'catch-up' on delays in meeting targets overtime.

4.4   Program strengths and challenges

In considering the achievements and implementation experience of jurisdictions to date, this Mid-Term Review has sought to identify Program strengths and challenges to inform future directions for the next three years of implementation. The implications of these are further explored in the following chapter of this report.

4.4.1   Program Strength – Flexibility in Program design

Flexibility for jurisdictions

The support by the Australian Government for the jurisdiction's to approach implementation consistent with local service systems and policy context has enabled creative solutions to be developed to respond to the needs of individuals and local circumstances. The flexibility within the Program structure has allowed jurisdictions to balance their focus on each of the POs differently, at varying stages of the Program. This has been a critical success factor as the social and economic situations across jurisdictions are diverse.

For example:

In Queensland…	Significant advances were made in the development of capital in the early stages of the Program. Accommodation to support up to 34 people has been built or modified in Brisbane, Gold Coast and Far North Queensland, with further facilities expected to be completed in Brisbane and the Sunshine Coast in 2009.
In the Australian Capital Territory…	The initial focus was on the completion of a five-bedroom home to accommodate four clients, plus an additional room for families.
In Western Australia…	The overheated economy as a result of the mining boom made access to contractors to build or modify facilities a lengthy waiting process. The focus has therefore been on developing services to divert people from entering RAC.

In the Northern Territory…	The Northern Territory Emergency Response (NTER) resulted in many people moving in and out of their homes and communities. This delayed the start of the Program, as invitation letters sent to many younger people with disability, their family or guardian were never received.
In New South Wales…	The initial focus has been on PO2 and PO3 through the development of In-Reach and In-Home packages which offer recreational and diversional therapy and allied health services such as physiotherapy.
In Tasmania…	The provision of transport has been identified as a significant issue for clients wanting to access allied health services, respite or attend social functions. Taxi fares have therefore been a common component of some aspects of the Program.

The different context and priorities across jurisdictions has provided, and will continue to provide, useful learnings to be shared and potential overall efficiencies for the Program. Representatives from Victoria have for example visited Queensland as part of good practice information sharing on the Queensland experience in developing capital provisions. The plans developed by Queensland for purpose designed and built housing have also been shared across jurisdictions.

A further example of the flexibility afforded to jurisdictions is the different role negotiated for ACATs/ACAS across the Program. Traditionally, ACATs/ACAS conduct assessments to facilitate entry into RAC across all jurisdictions. Their involvement in the Program is therefore crucial, either in supporting the assessment of younger people with disability, or referring younger people with disability to the YPIRAC Program for assessment. This process will be critical to the success of the Program following the initial five year funding period.

For example:

In Victoria…	The Program is providing an opportunity to strengthen relationships with ACAS. An existing Protocol between disability services and ACAS has been enhanced to ensure the unique needs of younger people with disability are reflected.
In Tasmania…	ACATs are an integral part of the Program; they conduct the client assessments as they would with any other person that may enter RAC.

National guiding principles for the assessment and coordination of services by ACATs :

▪ It is noted that a set of national guiding principles for the assessment and coordination of services by ACATs is currently being finalised. The guidelines will promote national consistency in the role of ACATs, including the assessment of the needs of younger people at risk of entry into RAC.

▪ Given the important role ACATs could have in the YPIRAC Program, either as assessors or in referring younger people at risk of entry into RAC, the national formalisation of their role will be an important step in embedding the consideration of the needs of younger people with disability into their practice.

Flexibility in service provision

Reflecting the complexity of the target group including age, medical condition, living arrangements, individual and family desires and geographic constraints, the flexibility of the Program structure has allowed jurisdictions to tailor responses to individual needs.

Jurisdictions have invested significant time and resources into the development of tools to collate narratives to understand the needs and desires of clients and their families. This will result in the delivery of services that are tailored to the specific needs and desires of clients.

For example:

In Victoria…	The individualised nature of the Program is best communicated by its title, *my future my choice*
In South Australia…	*My Story*, an assessment component designed to capture detail about clients, who they are and what they would like, and is completed with each YPIRAC Program participant.
In Western Australia…	The Program aims to understand what individuals want for themselves and their future as a key component of the initial assessment. There is a significant focus on collecting qualitative data about lifestyle aspirations.
In the Northern Territory…	Narrative reports have been identified as being *enormously helpful* in implementing the Program.

The following example from the Victorian Department of Human Services provides an indication of quality of life improvements for younger people with disability who have received supports to exit residential aged care into a more age appropriate alternative:

Cam is in his mid 40s and had been living in residential aged care for many years. In early 2008, Cam was supported to move to a new house in the community, with five other younger people with acquired brain injury.   Cam really likes living with other younger people because, as he says, "they aren't old and deaf" like the residents in aged care. At his new home, Cam likes to help with menu planning and cooking. He is always out and about during the week at various clubs and activities, including volunteer work at a leisure centre. Cam's friends have really noticed the difference living in the community has made to him. He has become more assertive and is exercising a lot more choice.

The following example from the Victorian Department of Human Services provides an indication of the individualised nature of support provided by the Program:

Bruce is a 22 years old and has spent most of the last year living in hospitals after an accident that left him a quadriplegic. He was at risk of being admitted to residential aged care because of his high level of support needs. Instead, Bruce has been supported to return to his family home, where he now lives with his mum, dad and two brothers. One thing that Bruce really likes about being back at home is having his dog around all the time. He is now settling back into a normal routine. His brother says that one of the best things about having him back home is that 'the whole family can eat dinner together now.' Now that Bruce is home from hospital, it is also much easier for his friends to visit. The hospital was two hours away by train and it was difficult for his friends to get to. Bruce now has a support worker to help with his morning routine, and one in the afternoon to support him to go out and visit friends, or go shopping or to the movies. Like any younger person, Bruce is thinking about what he wants to do in the future.

The following example from Tasmania provides an indication of the individualised nature of support provided by the Program:

One individual at commencement of the Program was only able to walk very little and mostly used a wheelchair to get around. The Program funding paid for taxis and gym membership, enabling the individual to take regular exercise. As a result the person is now very active, has lost weight and has experienced significant positive health outcomes.

4.4.2   Program strength – innovative delivery across governments and NGOs

Joined-up services

A further benefit of the Program's flexibility is that it has allowed for jurisdictions to engage with and across their own government agencies and service delivery contexts to meet the needs of the Program. The complexity of the YPIRAC Program and its overlap across the health, disability, housing and aged care portfolios of State/Territory governments, has highlighted the need for an increase in coordination in responding to the needs of this target group.

This is likely to result in long-term sustainable change to the way State/Territory Government departments consider their role in supporting younger people with disability.

For example:

In Victoria…	Step up/step down Programs attached to acute hospitals allow time for a client to stabilise, in the case of degenerative disease progression, or recovery from trauma of injury, prior to making premature decisions about placement into RAC. This delay provides an opportunity to demonstrate the potential benefit of having access to rehabilitation services and living in community settings rather than RAC. This is an important strategy given that in Victoria, 65 per cent of YPIRAC come from a hospital or rehabilitation setting.
In New South Wales…	A one-off grant was provided to NSW Health to respond to the equipment requirements of clients being diverted away from RAC and into community settings.
	Work is also underway with Housing NSW to ensure relevant services are able to work towards rehousing clients in the most appropriate facilities.
	Clients are also screened by referral and intake team tools to determine whether they are eligible for other community-based services and Programs.

Example of Good Practice (QLD) – Collaboration between multiple agencies:

A man with an acquired brain injury was able to return to live with his partner and their two young children. Funding through YPIRAC enabled his wife to have assistance from disability support workers so she could sustain her roles as wife and mother as well as providing care. The family's home could not be modified, so the Department of Housing provided a wheelchair-accessible unit for the family. Hospital staff assisted in developing a transition plan and assisted with assessments for aids and equipment and provided training in health care procedures to support workers and his partner. The collaboration between the Department of Housing, the hospital, the disability service provider, Disability Services Queensland and the family ensured a safe and successful transition from hospital.

Strategic Partnerships

The Program structure has also allowed for the establishment of strategic partnerships with non-government organisations and peak bodies to facilitate the implementation of the Program across jurisdictions. This is particularly important in acknowledging the complexity of the service infrastructure that is required to support younger people with a range of disabilities. Engaging with peak bodies and service providers that have specialist understanding of different conditions enables the Program to develop tailored responses to individual needs.

For example:

In South Australia…	The YPIRAC Program has worked in partnership with other government and non government organisations to access capital works and build a range of supported accommodation cluster sites across the State.
In Queensland…	Partnership with non-government organisations has resulted in the contribution of land, funding and expertise to support capital development and improvement work being conducted as part of the YPIRAC Program.
In New South Wales…	The YPIRAC Program Working Group has included the Younger People in Nursing Home National Alliance, Brain Injury Association, Aged Care Association of Australia and Aged and Community Services Association of NSW and ACT, to support the provision of expert advice in the development and ongoing implementation of the Program. Funding has also been provided to the Multiple Sclerosis Society for the Continuous Care Pilot, to support people with degenerative neurological conditions remain living in the community longer, and reduce the likelihood of entry to residential aged care . The project is being managed by the Multiple Sclerosis Society of NSW.
In Victoria…	The Continuous Care Project to support people with degenerative neurological conditions remain living in the community longer and reduce the likelihood of entry to RAC is being managed by the Multiple Sclerosis Society of Victoria.
In the ACT…	A strategic relationship with the National Brain Injury Foundation has facilitated the transfer of an YPIRAC Program client into their service.

The following example from Western Australia provides an indication of quality of life improvements for service users:

Will is a 45 year old man diagnosed with Multiple Sclerosis (MS) at 28 years of age. Following the diagnosis, he and his wife built a wheelchair accessible house with a modified bathroom to accommodate any future physical disability.

Will's health and physical ability deteriorated to the point where he requires 24 hour care. The family was receiving a small amount of in-home support and respite through Home and Community Care (HACC) funding and the Multiple Sclerosis Society, but the bulk of the care rested with his family. Even with extra support, his wife was unable to cope with caring for Will, raising two young children and working part time. Will was also suffering from regular chest infections, the last of which saw him admitted to hospital as it was no longer safe to discharge him to the family home without extra hours of paid support. While in hospital, Will was unsuccessful in obtaining funding through the normal Combined Applications Process, and therefore arrangements were being made to admit him to residential aged care.

Will was assessed as being eligible for YPIRAC funding because of his imminent admission. Anecdotal evidence demonstrates a much greater life expectancy for people with multiple sclerosis if they are cared for in a familiar and loving home environment as opposed to an institutional setting like an aged care facility. The MS Society reassessed Will's support needs and applied to YPIRAC for an appropriate level of recurrent funding to increase the paid support hours being delivered in the family home. Will was discharged from hospital in February 2007 and is being cared for at home through a combination of paid support via the YPIRAC program and

The Program strengths and achievements to date have been delivered with effective Australian Government support in Program design, management, coordination and administration. This has enabled the jurisdictions to flexibly respond to their own contexts and to develop innovative service delivery arrangements to meet client needs.

4.4.3   Challenge - Setting and meeting Program targets

This section frames the analysis of this Mid Term Review and underpins the recommendations for the future of the Program, which are outlined in the following chapter.

The challenges include factors outside of the Program control which impede their capacity to meet targets, specific constraints in regional and remote locations and the challenges of planning for clients with long-term, complex support needs.

Limited information about the client group, their circumstances and needs

At the commencement of the Program it was difficult to accurately establish targets given that most jurisdictions had little experience with, and knowledge of the YPIRAC client group, their current circumstances and their needs and wants. Necessarily - there were some assumptions made at the beginning of the Program which then formed the basis for the establishment of targets.

Given the limited knowledge of the YPIRAC target group, the targets set out in the Bilateral Agreements represent a 'best guess' as was stated by one of the jurisdictions.

Clients in the Program have varying levels of support needs. Some jurisdictions when forecasting Program costs for example, made assumptions that the client group would be evenly split across the four levels of support – low, medium, high and very high. In reality the majority of clients have either high or very high support needs.

Because of this limited knowledge at the beginning of the Program, most jurisdictions did early Program planning; undertaking research and consultation to enable them to better understand stakeholder needs.

For example, in Tasmania and Victoria, the Summer Foundation was engaged to develop profiles of the YPIRAC client group and identify their experience, social and medical needs and conditions, to further inform the development of YPIRAC Program.

Varying needs across age ranges and geographies

While the initial priority focus of the Program is people under 50 years old, there are a significant number of potential service users aged 50 to 65 years and in some jurisdictions people under 30 years that also require Program support. In most jurisdictions, the Program has been unable to cater for demand outside the priority age focus of the Program.

For example the Northern Territory indicated that many clients under the age of 30 (as opposed to those aged under 50 years), have significant support needs, and there was a need for the Program to consider prioritising this *younger* under 30 age cohort. By contrast, a 2005 Queensland study (2005, 7) found that of the under 50 years old YPIRAC Program target group, 73.7 per cent of YPIRAC were between 40-49 years, with 4.3 per cent under the age of 30 years.

In addition, the majority of jurisdictions indicated that while the five year Program targets will be achieved this will still leave an unmet need for a large number of YPIRAC.

Meeting targets in the early stages of the Program

Across jurisdictions the Program is mostly referring clients to new service arrangements or accommodation. At the beginning phase of the Program there is inevitably a time lag between assessment and the availability of places. Delays in finalising capital works in most jurisdictions have proved to be a particular challenge when diverting or relocating clients.

The time lag in the availability of services and facilities is particularly problematic when dealing with clients that have degenerative conditions and changing needs over the waiting period. It should be noted that additional assessments and client reviews are necessary when dealing with this client group, which can have impacts on timeliness of service delivery.

Jurisdiction specific challenges in achieving net reductions

While it is expected that overall the national net-reduction of YPIRAC clients will be achieved over the five years of the Program, jurisdictions have indicated that they have limited control over additional younger people entering RAC.

Much of this relates to jurisdictional specific criteria or conditions which may contribute to increases in the YPIRAC population. Some examples are outlined below:

- In South Australia and Victoria, not all YPIRAC are eligible for the Program. Under the Victorian Disability Act (2006) there are a number of YPIRAC who do not have a disability (as defined) and are therefore not part of the Program.

In these situations YPIRAC have a mental illness but no associated or co-existing disability, or were compensable clients. It is estimated that up to 6 per cent of the Victorian YPIRAC target group falls under this category.

- In Queensland and South Australia, some of the Aboriginal Nursing Homes that have clients in the YPIRAC Program are not classified as Commonwealth funded homes. Therefore any diversion of clients from these is not considered in the overall net reduction of clients.

- In Victoria, there are four residential care services known as 'specialist RACs'. These target younger people with needs such as mental illness, neurological, slow stream rehabilitation, or drug or alcohol related ABI. At October 2008, 18% (or 36 people) of the 202 people aged less than 50 were living in these specialist RACs. The capacity to achieve an overall net reduction in this circumstance is hampered as these services are considered in the overall RAC data, but as soon as a young person is supported to exit or diverted as part of the YPRAC Program, the specialist RAC fills the vacated spot with a new younger person.

- Jurisdictions have reported that many YPIRAC are not willing to relocate. This is particularly the case in regional areas, as this would result in many clients moving away from their families and support networks. In Victoria for example, up to 43 percent of YPIRAC had not consented to participation in the YPIRAC Program, either due to the fact that they are happy with current arrangements, or did not respond to invitations. Similarly almost 50 per cent of YPIRAC had indicated after their initial assessment that they did not want to relocate.

- Jurisdictions have reported difficulty in predicting the target group at risk of entering RAC. As part of meeting PO2, it is important to be able to plan for provisions for future Program recipients and future resource requirements.

Regional and remote areas

There are significant challenges in responding to the needs of YPIRAC in rural and remote areas. The challenges include the following:

- Many regional areas are sparsely populated with insufficient critical mass of clients and services to cost effectively deliver community-based accommodation or services.

- The YPIRAC Program responds to varying medical conditions, disabilities and changing needs of many high support need clients. Even in larger regional areas where more than a number of YPIRAC Program clients may be based, developing a cost-effective, individually tailored delivery model can be very challenging.

- In many instances clients express a preference for placements in locations where they grew up or are familiar with. These are often not available in regional and remote areas. Clients therefore remain in RAC because of lack of alternatives.

There have been some innovative responses to these challenges within the Program. In Queensland, clients supported under the YPIRAC Program in remote areas share arrangements with clients supported under other funding Programs. Each funding Program contributes a proportion of funding based on their client needs. Similarly in Victoria in some instances, YPIRAC and older carer Programs combine funding to create a more sustainable pool of service delivery for a larger client group.

The YPIRAC Program Victorian model has also funded a support person to implement the Program regionally. The support person is responsible for direct communication with Program clients and their families, as well as the coordination of support packages.

4.4.4   Challenges – Planning future service delivery

Clients with high-level complex needs require security in their support arrangements which have to be able to respond to their current and future needs. This places demands on Program capacity for continuity of service, planning for 'whole of life' as well as for key transitions and changing rehabilitation, health and other support service needs.

Program continuity

Service users are concerned that the lack of recurrent funding beyond the initial five-years of the Program will place their support arrangements at risk in the future. This is of particular concern for people who are currently settled in RAC who are being asked to considering relocating, as their current arrangements appear to provide them with future security.

Linked with this Program, managers indicate that service users have expectations of recurrent funding. Currently, there is a lack of information about exit strategies to support clients should on-going funding not be available.

Furthermore, Program managers have found that the lack of clarity around recurrent funding has also contributed to a high turnover of YPIRAC Program staff. In NSW for example, all YPIRAC Program appointments are made on a temporary basis. In Tasmania, the YPIRAC Program manager position has been held by three different people.

It is noted that the Bilateral Agreements contain a provision of ongoing funding, should a five-year evaluation support the Program's overall success and cost-effectiveness.

Transition planning

Transition planning has been defined by jurisdictions in a number of different ways:

- Transition from RAC to new accommodation: The need to provide equipment and support to families and clients as they relocate from hospital or RAC into their homes or new accommodation.

- Transition necessitated by increasing support needs: The need to develop Program responses to assist clients as their support needs increase, particularly in relation to degenerative illnesses. This may require them to re-enter RAC.

- Transitions required by changing needs over time: The need for the Program to respond to different medical conditions, support needs or client desires, that may develop during their lives.

The Summer Foundation report into YPIRAC in Victorian found that of the research participants, 58 per cent had entered RAC due to an increase in their needs and 16 per cent had been cared by someone who was no longer able to care for them. Seventy-seven per cent of YPIRAC had four or more medical conditions, with 52 per cent utilising five or more items of specialised equipment (2007, 17-100).

In Queensland, the YPIRAC Program has developed strategies to assist with managing transitions by taking a continuum of care approach to enable the Program to respond to the changing needs of clients throughout their life course. Similarly Victoria has developed strategies such as the Continuous Care Project with the MS Society to manage degenerative neurological conditions and delay as much as possible entry or re-entry into RAC.

Rehabilitation

In their analysis of the YPIRAC Program initiative, Foster, Fleming and Tilse (2007) identified people with ABI as the single largest category of YPIRAC, accounting nationally for 30 per cent of clients. Reporting by jurisdictions supports this.

Foster et al (2007, 314) argue that supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services and identifies this as a key challenge for the YPIRAC Program. They argue that the YPIRAC Program should place people with ABI and their families inside of and with clear access to the health and rehabilitation systems and specialist frameworks that have been designed to promote recovery for this population. Rehabilitation is currently outside the scope of the YPIRAC Program.

The importance of an ongoing rehabilitation regime in managing many complex conditions is well understood within the Program. The need for increased Program focus on this has been identified by some jurisdictions as an important future challenge for the Program.

4.4.5 Challenge - communicating the complexity of client needs and the service delivery context

As with all government programs, there are demands on jurisdictions to report quantitative achievements and data on clients to enable confidence in program achievements and expectations about efficiency and accountability. Reporting by governments is therefore less likely to include qualitative information that may be available regarding programs, including information which demonstrates the texture and the challenges of program implementation. However, it is acknowledged that the opportunity to consider qualitative outcomes will be addressed in formal program evaluations and reviews.

This document, through the use of examples seeks to contribute to this qualitative understanding.

4.5 Mid Term Review – discussion of conclusions

This Mid-Term Review has concluded that jurisdictions have made significant positive progress in implementing the Program to date. There is a body of quantitative and qualitative data to support the conclusion that the Program is having a very positive impact on younger people with disabilities who either reside in, or are at risk of entering, RAC.

While most jurisdictions reported initial delays in developing processes, recruitment and capital works, it is expected that the impact of these will be contained to the first two years of Program implementation. These provide the necessary Program building blocks for future delivery. These foundations will support meeting Program placement targets over the five years of the Program.

4.5.1 Current progress toward the objectives

Overall, data indicates that the Program target to achieve a national net reduction in the number of YPIRAC by between 425-689 is likely to be achieved within five years as per original Program forecasts. This conclusion is based on data provided by jurisdictions, analysis of the net number of YPIRAC in 2006 and 2008, and the percentage of Program funding that is still to be provided to each jurisdiction.

Despite early delays in meeting these targets, and particularly the inconsistency of actual targets in relation to those forecast across each of the POs, a net reduction of 149 YPIRAC has been achieved (see table 13).

Of particular importance is that 296 (51%) clients were relocated or have agreed to be relocated from RAC as part of the YPIRAC Program and 125 (21.5 %) were deemed at risk of entry into RAC.

These findings are particularly interesting given that most jurisdictions have indicated relatively slower progress towards achieving targets for PO1, as capital works have not been completed at this stage of implementation and the large number of diversions reported as part of PO2.

Table 13 –net reduction in YPIRAC 2006-2008

	NSW	VIC	SA	QLD	WA	TAS	NT	ACT
No. of YP in RAC (0-49 yrs old) in 2008	336	209	55	179	58	11	6	4
No. of YP in RAC (0-49 yrs old) in 2006	391	221	60	244	65	15	7	4
Drop (2006 to 2008)	-55	-12	-5	-65	-7	-4	-1	0

Source: Australian Institute of Health and Welfare, YPIRAC Program Final Report on the 2007–08 Minimum Data Set, Table 5.2 (N.B this data includes young people with disability in residential aged care who have died or aged out of the Program)

As previously noted, jurisdictions have indicated that they expect further achievements in the next Program period, particularly as capital works are finalised. This is supported by the percentage of total Program funding that will be provided to jurisdictions in the final two years of the Program – in most cases 62% of Program funding is yet to be provided (see table 14).

Table 14 – Program Funding

Jurisdiction	Funding provided in 2006-07	Funding provided in 2007-08	Funding provided in 2008-09	Total remaining funding ($) to be provided in 2009-10 and 2010-11	Percentage of total Program funding to be provided in 2009-10 and 2010-11
NSW	$1,332,422	$4,663,477	$9,326,954	$25,316,018	62
VIC	$987,746	$3,457,111	$6,914,222	$18,767,172	62
QLD	$782,503	$2,738,759	$5,477,518	$14,867,488	62
SA	$301,714	$1,055,998	$2,111,995	$5,732,558	62
WA	$397,012	$1,389,543	$2,779,085	$7,543,232	62
TAS	$95,103	$194,166	$1,031,250	$1,580,130	54
NT	$39,838	$139,433	$278,865	$756,921	62
ACT	$253,798	$540,744	$367,511	$779,655	40

When looking at the individual performance of jurisdictions to date, for example, (see table 15), it is evident that in some instances there appears to be underperformance, particularly around PO1.

It was originally anticipated that by the conclusion of the 2008-09 financial year, between 188-241 people would have been relocated from RAC (PO1). At the December 2008 reporting period however, the total number of YPIRAC relocated was 70.

For example:

In New South Wales…	Original forecast to relocate between 44-88 people by June 2009, had achieved 2 relocations by December 2008.
In Victoria…	Original forecast to relocate 71 people by June 2009, had achieved 19 relocations by December 2008.
In Western Australia…	Original forecast to relocate 12 people by June 2009, had achieved 3 relocations by December 2008.
In South Australia…	Original forecast to relocate 24 people by June 2009, had achieved 17 relocations by December 2008.
In Queensland…	Original forecast to relocate between 35-43 people by June 2009, had achieved 25 relocations by December 2008.

Jurisdictions have indicated that in the fourth and fifth year of the Program, they expect a significant increase in the number of clients relocated from RAC. Much of this delay has been attributed to the development and/or modification of capital provisions.

Further progress towards achieving original targets will make a significant numerical contribution towards achieving an overall net reduction nationally.

Table 15 – PO1 and PO2 achievements as reported by Jurisdictions in the December 2008 reporting period

	NSW	VIC	SA	QLD	WA	TAS	NT	ACT
PO1	2	19	17	25	3	1	2	1
PO2	2	41	19	35	16	3	6	7
Total	4	60	36	60	19	4	8	8

This Review notes that:

▪ Many jurisdictions will be unable to achieve their five year targets until years four and five, as the development of capital, which takes significant time, is finalised. Table 16 provides a summary of the current progress towards achieving forecast objectives.

▪ While overall Program targets will be achieved, these may not represent the anticipated distribution of clients across PO1, PO2 and PO3, as outlined in the Bilateral Agreements.

▪ Jurisdictions have very limited control over the factors that influence younger people entering RAC and whilst forecast targets, at this stage are likely to be achieved, these cannot be guaranteed due to a range of previously discussed factors outside the control of the Program.

Table 16 – Current progress towards objectives

Priority Objective and focus	Desired Program outcome	Current progress toward the objective
One – Relocation of current younger people in RAC care facilities.	Net reduction in numbers of younger people in RAC.	Limited number of service users choosing to relocate. In particular jurisdictions, up to 50% of service users have indicated that they will not be relocated. Initial delays in the development of and modification of capital provisions. It is expected that targets will be met by years four and five.
Two – Diversion of younger people at risk of entering RAC.	Reduction in new service users entering residential aged care therefore preventing a net increase in new admissions of younger people into RAC. Net reduction in numbers of younger people in RAC.	High success in service user engagement with overachievement in this target area by many jurisdictions. Given the large number of clients with high and very high needs, this has attracted higher costs that those initially anticipated. To ensure service provision in remote or rural areas, Program funding in these instances has often been combined with other Programs.

Priority Objective and focus	Desired Program outcome	Current progress toward the objective
Three – Supporting younger people in RAC.	Supporting younger people in RAC to enhance quality of life outcomes.	High success in service user engagement and a range of strategies to enhance quality of life.

5   Mid-term review implications

5.1   Overview

This chapter follows from the discussion outlined in Chapter Four and utilises the structure of those findings as the basis for ordering these conclusions and recommendations. These include the YPIRAC Program strengths and challenges, and presents the rationale for a set of recommendations to enhance the future of the Program.

5.2   This review

In the Bilateral Agreements establishing this Program, the Commonwealth, State and Territory Governments agreed that the Mid-Term Review would assess whether the Program is achieving its stated outcomes in respect of the:

▪   Objectives

▪   Agreed interim performance targets

▪   State/Territory specific issues in each Bilateral Agreement.

As set out in the introduction of this report, this Mid-Term Evaluation has taken place within a context of:

▪   Implementation of the Program commencing at different times in each jurisdiction, due to Bilateral Agreements being concluded within a period between August 2006 and January 2007

▪   An initial emphasis being placed on the conduct of functional needs assessments of those people in the initial target group, being people aged under 50 years and currently in RAC.

The methodology as outlined in the terms of reference for this review included:

▪   Liaising with the government departments in each state and territory responsible for implementing the YPIRAC Program, to collect the required information, using existing data sets and reports wherever possible.

▪   Undertaking an analysis of that information.

▪   Reviewing the Program against the evaluation criteria as outlined.

The key review questions this Mid-Term Review aims to answer are:
▪   Were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?

▪   How is the Program being implemented in each State and Territory as set out in Bilateral Agreements, and what are the challenges and issues impacting on the Program?

▪   To what extent will the funding available to States and Territories meet the demand for support required by the YPIRAC initiative?

5.3   Limitations of this review

There are two main limitations in the conduct of this review.

5.3.1   Extent to which Program funding will meet demand for support

This Review is unable to draw conclusions regarding the extent that the Program funding available to States and Territories will meet the demand for support required by the YPIRAC initiative.

While Program funding will be sufficient to support the achievement of the number of targeted net reductions as outlined earlier, a significant demand for services for YPIRAC will remain, particularly for clients with very high needs and for those in rural and remote locations. This is largely because the Program has little if any control over the numbers of potential clients of the Program who may be admitted to RAC over its duration.

Furthermore, factors such as the availability of suitable housing, planning and development constraints, overall service system capacity, allocations of and build time for capital works, and staffing availability, are all largely matters outside the control of the Program. The adequacy of funding amounts available for each placement, or to meet each objective cannot be assessed by this Review, as this would require both information not available to the Review team and a different methodology.

We recommend that the assessment of the adequacy of the funding for placement, diversion or enhancing quality of life be addressed at the conclusion of the initial five-years of implementation.

5.3.2   Quality of Life Indicators

It is noted that one of the original Program measures was intended to be the number and percentage of YPIRAC Program clients who report that the new arrangements have enhanced their quality of life.

It is understood that the Social Policy Research Centre (SPRC) was commissioned to identify a tool to measure quality of life outcomes for people involved in the YPIRAC Program. While this report has been informed by the May 2008 draft report from the SPRC, it is understood that to-date, the measurement tool has not been finalised. Quality of life data was therefore unavailable for the Mid-Term Review.

The delay in finalising the measurement tool has prevented the introduction of a standardised approach to gathering qualitative YPIRAC Program data across the jurisdictions.

When referring to Quality of Life outcomes, this Review has adopted the generic definition contained in the SPRC report which states that Quality of Life is influenced by a number of domains including material/financial wellbeing, health, personal relationships and social interactions, feelings of safety and socio/economic factors (social, leisure, workforce and educational participation). It is noted that the SPRC identifies community engagement as one of the key Quality of Life indicators for YPIRAC Program clients.

5.4   Summary of review findings

While it has been noted that much of the early YPIRAC Program planning made assumptions about the client group, their level of support needs and whether they wanted to move from residential aged care, this mid-term review analysed information and data about the Program and consulted with jurisdictions to provide an analysis of the Program strengths and challenges.

A summary of findings in relation to the key evaluation questions is presented in Table 17.

Table 17 – Summary of review findings

Key review question	Summary of Program actual experience	Summary of mid-term review findings
Were the Bilateral Agreements underpinning the Program designed to allow the objectives for the Program set out by COAG to be met?	▪ Given the limited evidence available regarding the YPIRAC Program target group, Bilateral Agreements made a number of assumptions regarding Program targets and timeframes based on the best evidence available at the time of the Program inception. ▪ The inaccuracy of some of these early assumptions, particularly in relation to the levels of YPIRAC client needs, and the cost in providing support services, have created challenges for some jurisdictions. ▪ A number of jurisdictions have renegotiated their targets and/or the timing of funding to reflect the actual experience in implementing the Program. ▪ The Department of FaHCSIA has supported the review of targets and funding arrangements as needed.	▪ The use of Bilateral Agreements for the Program engages the relevant agencies across levels of government and jurisdictions. They enable high level commitment from participating agencies and ensure that Minsters and relevant department heads are in agreement with the Program and its objectives. ▪ While it is always a judgement and sometimes an expectation that the means to achieve program objectives are detailed, the inherent flexibility required to meet the complex needs of YPIRAC clients demands an approach which allows each jurisdiction the means to achieve those targets over the life of the Program. ▪ It may have been more useful to provide overall targets for each jurisdiction, for example to achieve a net-reduction of 200 YPIRAC within five years, rather than specific targets for each PO and for each year of the Program implementation. ▪ The inclusion of PO3 in the bilateral agreements seems to contradict the Program's primary focus of relocating YPIRAC or diverting people at risk of entry to RAC. PO3 does not support a net-reduction in YPIRAC.
How is the Program being implemented in each State and Territory as set out in Bilateral Agreements, and what are the challenges and issues impacting on the Program?	In summary Program strengths are: ▪ Jurisdictions have benefited greatly form the flexibility in the Program design. Jurisdictions have been able to prioritise PO, define target groups and allocate funding to reflect their policy, legislative and service delivery environments. This has allowed for the development of the Program in a different way across jurisdictions – ensuring that Program implementation is efficient and reflective of local structures.	▪ Significant progress has been achieved nationally in providing genuine individualised alternatives to inappropriate admission RAC for younger people with disability in a flexible and tailored service environment. This has been achieved through the development of strategic partnerships across/within governments and with the non-government sector, in a complex service interface between health, housing, aged care, disability, community services.

Key review question	Summary of Program actual experience	Summary of mid-term review findings
	- Some jurisdictions have built on existing government structures and service delivery models to implement the Program in genuine 'joined-up' government settings. These approaches reflect the complexity of the Program's operating environment and the necessary overlaps across the health, disability, housing, community services and aged care portfolios. These are good practice implementation approaches that will support sustainable outcomes for clients beyond the 5 year cycle of the Program. - Given the complexity of the Program in responding to so many varying individual needs of clients and their families, many jurisdictions have implemented productive partnerships with NGOs who have the expertise and service infrastructure to support the client-group. This has produced efficiencies across the Program. In summary, Program challenges are: - The initial five-year funding period for the Program has been reported as a disincentive for participation by some YPIRAC. Similarly, the lack of recurrent funding has required jurisdictions to recruit Program staff on a temporary basis, making staff retention difficult. - Jurisdictions have identified a shortage of staff experienced in transition planning to assist clients in their relocation from RAC to new accommodation, and to respond to their changing needs (particularly in degenerative illnesses). - Given the large percentage of clients with ABI and the known importance of an ongoing rehabilitation regime in ensuring enhanced quality of life outcomes, the need for increased Program focus on this area has been identified by some jurisdictions as an important future Program direction. - Many jurisdictions have invested resources in collating rich	- Jurisdiction have developed strong informal and information sharing networks across the Program nationally, sharing experiences and resources in an environment of cooperation. This is producing efficiencies across the Program nationally, reducing the likelihood of duplication, and ensuring that solutions to common problems are shared. In responding to identified Program challenges it is noted that: - There are a number of good practice strategies adopted by individual jurisdictions that can be further promoted nationally, particularly in responding to the needs of YPIRAC Program clients in regional and/or remote locations. This includes the employment of YPIRAC regional coordinators, and the pooling of funding from a number of programs to create a larger client mass and support the establishment of service infrastructure. - Clarification regarding Program continuance and exit arrangements for current YPIRAC clients and staff is needed to manage concern regarding the future beyond the initial five-year commitments. - There is a need for further national Program support and training regarding transition planning. - There is a need for the YPIRAC Program to ensure that people with ABI and their families continue to have clear access to the health and rehabilitation systems and specialist frameworks that have been designed to promote the wellbeing of this population - The Program reporting focus, particularly from the perspective of the AIHW, has been on quantitative data. This makes it difficult to demonstrate Program achievements through the rich narratives of qualitative information that have been recorded by jurisdictions. These narratives demonstrate the complexity of the service

Key review question	Summary of Program actual experience	Summary of mid-term review findings
	bodies of qualitative data regarding the needs and desires of individual Program clients. This investment has allowed the Program to identify and respond to the specific needs of clients and their families extremely successfully.	delivery environment in which the Program is operating, and also provide tangible evidence of the significant positive impact the Program is having on individuals and their quality of life outcomes.
To what extent will the funding available to States and Territories meet the demand for support required by the YPIRAC initiative?	▪ The under 50 years of age target group has been identified as the priority Program target group in most jurisdictions, although YPIRAC terminology also includes the 50-65 years age cohort. ▪ Initial delays in meeting forecast targets. Some jurisdictions have significantly underperformed in meeting targets for PO1 and PO2 for the initial three years of Program implementation. ▪ Underperformance can be attributed to delays in understanding the needs of the target group, the development or modification of capital and contacting and/or engaging clients. ▪ Initial funding allocations in some jurisdictions, underestimated the large number of high need clients, and therefore the costs associated with providing support services.	▪ It is expected that the target net reduction nationally will be achieved within the current funding allocation and timeframe. ▪ Given that in most jurisdiction, 62 per cent of funding is scheduled to be allocated in years four and five of the Program, it is expected that a significant increase in meeting PO targets will take place over this period. ▪ There is significant unmet need of YPIRAC, both in the under 50 years target group, and particularly the 50-65 years target group. While the Program will make a positive contribution to this previously neglected group, many YPIRAC will continue to have significant needs that cannot be met within current funding allocations. The Program has little control over the clients entering RAC over the life of the Program. This is particularly the case with YPIRAC in regional or remote areas, where the delivery of cost-effective services has been a challenge. ▪ A comprehensive cost-benefit Program analysis is needed to assess the initial and ongoing cost of the Program under each PO with particular attention to: future costs related to responding to changing client needs, the health and quality of life outcomes for Program clients and their families, and any efficiencies or savings that have resulted from the Program.

5.5 Short-term implications for YPIRAC Program

Based on the analysis presented in this and the preceding chapters, this Mid-Term Review has identified a number of recommendations to inform the remaining two-years of Program implementation. These are presented below with an accompanying rationale.

5.5.1 Promoting good practice in responding to the needs of YPIRAC clients in regional and remote areas

The Program's capacity to respond to the needs of YPIRAC in regional and remote areas is limited and has resulted in some clients remaining in RAC due to the lack of appropriate alternatives available locally.

The challenges in supporting YPIRAC in regional or remote locations are best summarised as:

- Availability of existing services in these locations which can cater for the target group.

- Cost-effectiveness of developing new service infrastructure or capital to support a small population.

This Review has noted that many jurisdictions have developed or utilised existing partnerships across government, or in the non-government sector, to support the implementation of the Program in various ways. Specifically in relation to supporting YPIRAC in regional or remote areas, the review has noted that:

- Some jurisdictions have employed regional coordinators to coordinate responses for clients in less centralised locations.

- Funding has been combined with other existing Programs in regional and remote areas to create a more sustainable pool of service delivery for a larger client group. In these, each funding Program contributes a proportion of funding based on their client needs.

In light of the good practice strategies being implemented across some jurisdictions and the challenges faced in others when responding to the needs of regional and remote Program clients, it is recommended that:

- The extent of unmet need of YPIRAC in regional and remote areas be determined in consultation with jurisdictions.

- The feasibility of employing, where appropriate, regional YPIRAC coordinators to support the development of tailored responses to YPIRAC clients, particularly in jurisdictions that are highly decentralised, be explored.

- Jurisdictions which have successfully developed funding pools with existing Programs in regional or remote areas be requested to share their experiences and the processes undertaken in establishing these.

5.5.2 Ensuring that YPIRAC Program clients and staff understand the future of the Program

There is concern by service users and YPIRAC Program staff, regarding the Program continuity beyond its initial five-year period.

Some jurisdictions have highlighted the need to provide clarification to existing and potential service users and staff regarding continuance or exit arrangements for the Program beyond the current five-year commitment. While the uncertainty regarding ongoing funding is inherent in any pilot program, given the high-level needs of clients, it is particularly important that clarification be provided on arrangements for existing Program clients should funding cease.

Jurisdictions reported that the lack of clarification has deterred potential service users from relocating from RAC and been an obstacle to the recruitment and retention of staff.

It is therefore recommended that:

- The Australian Government provide clarification to existing and potential service users and YPIRAC Program staff regarding continuance or exit arrangements for the program beyond the current five year commitment.

- If the Program does not continue beyond the current five-year commitment , recurrent funding is secured to ensure the needs of the current Program clients are met into the future.

5.5.3   Supporting YPIRAC Program clients and their families through change

The YPIRAC Program client group is highly susceptible to change. It is likely that as conditions degenerate, or, people age, their needs will change and require the review of current service infrastructure. As has been discussed in previous chapters, transition planning has been identified by a number of jurisdictions as an important component of the Program into the future.

Transition planning presents two key challenges for the Program:

- Resourcing - increased client needs may require accommodation modification, increased specialist services or equipment. This will put further pressure on the limited pool of Program resources and funding. Consideration of future Program funding in this context is critical to reduce the likelihood of client re-entry to RAC.

- Skilled workforce – the need for staff to understand the importance and engage in transition planning so that the changing needs of clients and their families can be managed and responded to. Jurisdictions have identified limited community sector-wide experience in providing transition planning support.

Given the likely demand for transition planning support and services by YPIRAC Program clients, and the identified knowledge-gap in the community sector, it is necessary to develop strategies to ensure the Program can respond to the changing needs of clients.

It is understood that the new National Disability Agreement has incorporated a significant sector-wide training component. In this context, it is also understood that there is scope to influence the national training agenda as part of the Commonwealth State and Territory Disability Agreement (CSTDA), and include transition planning as a sector-wide priority.

It is recommended that:

- Analysis of demographic projections is conducted to forecast the changing needs of YPIRAC Program clients and the resource implications of this over the next decade.

- The Australian Government provide support to YPIRAC Program staff to ensure that they understand and can respond to the transition planning needs of Program clients and their families.

- The provision of transition planning training for organisations and staff delivering services to YPIRAC be identified as a priority in the national training agenda developed as part of the CSTDA.

5.5.4   Analysing the rich narratives and stories that have been collected

While the AIHW NMDS reports provide a useful insight into the characteristics, clinical information and background of clients, the limited qualitative focus is inhibiting the ability to understand at a national Program level:

- The complexity of the Program's interface between the health, aged care, housing and community services sectors.

- The significant narratives and positive quality of life outcomes for individuals involved in the Program.

Given that many jurisdictions have reported the collection of rich narratives, it would be beneficial for this data to be collated and analysed to enhance the understanding of the Program implementation to date. This would be particularly important to inform the Program evaluation at the five-year period.

It is therefore recommended that:

- In consultation with jurisdictions, a template be developed to support the consistent collection and reporting of qualitative data in the future intake of YPIRAC Program clients. Given that a number of jurisdictions are expecting a dramatic intake increase in years four and five of the Program, the development of this template should be completed as a priority.

- Jurisdictions be requested to forward to FaHCSIA, any particularly significant qualitative data collected to date, and that this be reviewed as part of the final Program evaluation.

5.5.5 Understanding the real cost and benefit of implementing the Program

While it is expected that the desired net reduction in YPIRAC will be achieved within current funding allocations, it is important to establish what the real Program costs, benefits and savings have been.

While it should be relatively easy for jurisdictions to report on the cost of providing services to YPIRAC Program clients under each objective, a much more complex and robust analysis is required to determine whether the diversion or relocation of YPIRAC is producing quality of life outcomes that are manifesting into cost-benefit savings in the treatment of clients.

The evidence behind the development of this Program, as reflected in literature review, supports the fact that people who live in community settings have better health outcomes than those in RAC. Given this, it is reasonable to expect that this Program will produce a positive cost-benefit outcome for clients, service providers and governments.

It is therefore recommended that a cost-benefit analysis of the Program be commissioned, and that it considers:

- The adequacy of the funding for placement, diversion or enhancing quality of life of YPIRAC Program clients by comparing the level of YPIRAC service demand/need, and the cost of Program implementation.

- The health benefits and quality of life outcomes for people involved in the Program.

It is expected that this analysis will provide an evidence-base for the allocation of future Program funding and prioritisation of objectives.

5.5.6 Ensuring the Program can respond to the needs of clients with ABI

The analysis in the preceding chapter has identified literature alongside jurisdictional experience that emphasises the benefits for clients with ABI to participate in an ongoing rehabilitation regime. It has also been noted that this is highly specialised, and usually provided in the context of specialised facilities/accommodation.

Jurisdictions have expressed concern that the relocation of YPIRAC Program clients from RAC (PO1) and at times diversions from hospitals as part of PO2, because the client is assessed as being 'at risk' of entering RAC, removes clients with ABI prematurely from structured environments that have been established to support their ongoing rehabilitation.

In this context it is recommended that further research into the specific needs of YPIRAC Program clients with ABI be undertaken to identify whether their entry into the Program has been beneficial, and how the Program can best ensure access to the rehabilitation services they require within a community setting.

An important component in this assessment will be understanding how different jurisdictions are defining who is 'at risk' of entering RAC, and at what point they are recommending that clients with ABI particularly, relocate from hospitals or rehabilitation facilities to the YPIRAC Program. It is understood that there has been limited jurisdictional consistency regarding the definition of the 'at risk' target group.

5.6 Long-term direction for YPIRAC Program

Based on the analysis presented in this and the preceding chapters, this Mid-Term Review has also identified recommendations to inform the Program beyond its initial five-years of implementation should it continue.

5.6.1 Maintaining the Program focus on net-reductions

Reflecting the Program focus, the Bilateral Agreements emphasise the overall Program aim of achieving a net-reduction in the number of YPIRAC.

Despite this primary focus, the Program's PO3 reflects a focus on enhancing services for YPIRAC who do not relocate. In this context the Program aimed to acknowledge that alternatives cannot always be made available, and therefore the initiative included this option.

Achievements in meeting PO3 to-date, for example, highlight that jurisdictions have invested significantly in this target group. The cumulative target for the 2008-09 period was between 152-193 enhancements. By December 2008, 360 enhancements had been delivered nationally. In considering this data, it is acknowledged that some jurisdictions have reported that they are providing enhancements (PO3) to YPIRAC only in the short-term, until the development or modification of alternate accommodation is finalised for their relocation (PO1).

While the provision of enhancements within RAC can make a significant difference to the quality of life of people of YPIRAC, the focus of PO3 is on how RAC can be made more suitable to YPIRAC. This focus is very different from that of PO1 and PO2 – which concentrate efforts on relocating and/or diverting younger people from RAC.

In order to maintain the primary Program focus on achieving net-reductions in the number of YPIRAC, it may be more appropriate for PO3 to be implemented under a different Program structure. While ensuring outcomes for YPIRAC who do not relocate is important, its inclusion in the YPIRAC Program seems to contradict the foundation of the Program – *RAC is an inappropriate accommodation alternative for younger people with disability, and other options should be available*.

It is recommended that

- Future YPIRAC Program Bilateral Agreements refer only to the relocation of YPIRAC or diversion of younger people at risk of entry into RAC.

- The provision of enhancements for YPIRAC is continued under a different Program structure.

5.7 Linking Mid-term review conclusions and key evaluation questions

This Mid-Term Review provides seven recommendations to enhance the implementation of the Program.

The recommendations have been structured to reflect the themes of the key evaluation questions.

▪ Bilateral Agreements.	▪ See recommendation one regarding the need to provide clarification regarding the Program beyond five years. ▪ See recommendation two regarding the contradictory focus of PO3 in the current Program structure which prioritises a net-reduction in the number of YPIRAC.
▪ Program strengths and challenges.	▪ See recommendation three regarding the sharing of good practice strategies to respond to challenges in providing services in regional and remote locations. ▪ See recommendation four regarding the need to develop

	strategies to ensure the Program can support transition planning and the changing needs of clients.
	▪ See recommendation five regarding the Program benefits in analysing the rich narratives and qualitative data that have been collected by jurisdictions in assessing the needs of individual clients.
	▪ See recommendation six regarding the assessment of the needs of Program clients with ABI and how the Program is responding to these.
▪ Program funding and resourcing.	▪ See recommendation seven regarding the conduct of a cost-benefit analysis to assess the adequacy of Program funding in meeting the needs of the YPIRAC client group and assessing the Program's value-for-money.

Recommendations

Recommendation one

It is recommended that:

A. The Australian Government provide clarification to existing and potential service users and YPIRAC Program staff regarding continuance or exit arrangements for the Program beyond the current five year commitment.

B. If the Program does not continue beyond the current five-year commitment, recurrent funding is secured to ensure the needs of the current Program clients are met into the future.

Recommendation two

It is recommended that

A. Future YPIRAC Program Bilateral Agreements refer only to the relocation of YPIRAC or diversion of younger people at risk of entry into RAC.

B. The provision of enhancements for YPIRAC is continued under a different Program structure.

Recommendation three

It is recommended that:

A. The extent of unmet need of YPIRAC in regional and remote areas be determined in consultation with jurisdictions.

B. The feasibility of employing, where appropriate, regional YPIRAC coordinators to support the development of tailored responses to YPIRAC clients, particularly in jurisdictions that are highly decentralised, be explored.

C. Jurisdictions which have successfully developed funding pools with existing programs in regional or remote areas be requested to share their experiences and the processes undertaken in establishing these.

Recommendation four

It is recommended that:

A. Analysis of demographic projections is conducted to forecast the changing needs of YPIRAC Program clients and the resource implications of this over the next decade.

B. The Australian Government provide support to YPIRAC Program staff to ensure that they understand and can respond to the transition planning needs of Program clients and their families.

C. The provision of transition planning training for organisations and staff delivering services to YPIRAC be identified as a priority in the national training agenda developed as part of the Commonwealth, State and Territory Disability Agreement (CSTDA).

Recommendation five

It is recommended that:

A. In consultation with jurisdictions, a template be developed to support the consistent collection and reporting of qualitative data in the future intake of YPIRAC Program clients. Given that a number of jurisdictions are expecting a dramatic intake increase in years four and five of the Program, the development of this template should be completed as a priority.

B. Jurisdictions be requested to forward to the Department of Families, Housing, Community Service and Indigenous Affairs, any particularly significant qualitative data collected to date, and that this be reviewed as part of the final Program evaluation.

Recommendation six

It is recommended that research into the specific needs of YPIRAC Program clients with ABI be undertaken to identify:

▪   Whether their entry into the Program has been to their benefit

▪   How the Program can best ensure access to the rehabilitation services for client with ABI within a community setting

▪   How different jurisdictions are defining the 'at risk' client group under PO2, and the impact this is having on the client group, particularly clients with ABI.

Recommendation seven

It is recommended that a cost-benefit analysis of the Program be commissioned, and that it considers:

- the adequacy of the funding for placement, diversion or enhancing quality of life of YPIRAC Program clients by comparing the level of YPIRAC service demand/need, and the cost of Program implementation

- the health benefits and quality of life outcomes for people involved in the Program.

Appendix A   Literature review

Historically, the issue of accommodating young people with disability in residential aged care has been an issue of concern for young people with disability and for families, carers and advocates as an area of unmet need.

It is widely acknowledged in the disability sector that aged care facilities are not designed or adequately resourced to facilitate the active involvements of younger residents with high clinical needs in everyday activities or support their continues participation in the life of the community. This may be largely attributed to the design purpose being to provide accommodation, personal and nursing care to frail older people at the end stage of their life (Winkler et al: 2006, p 100). Winkler et al (2006, p 101) report that younger people are admitted to such facilities typically because more appropriate accommodation is unavailable.

The ageing of the population generally, associated with disability, places additional pressure upon residential aged care services, but also upon ageing parents and carers of younger people with disability, anxious to ensure their children or partners can have access to appropriate accommodation types and support services.

A.1.1 Younger people accommodated in aged care services

The Australian Institute of Health and Welfare (2008, p 42) reported that, nationally, in 2006-07, there were 6,613 residents aged less than 65 years accommodated in aged care services, comprising 4% of all residents. This pattern was similar across the States and Territories, with the exception of the Northern Territory, where the proportion of residents aged less than 65 years was considerably higher, at 13%. The different age profile in the Northern Territory is to be expected, given the proportion of Aboriginal and Torres Strait Islander peoples living in that Territory. Aged care planning for Aboriginal and Torres Strait Islander peoples includes those 50 years and over in light of their poorer health status. In remote areas, 9% of residents were aged under 65 years, while in very remote areas 19% of residents were aged under 65 years. In other regions, the representation of this age group was near the national average of 4% (AIHW 2008, p 42).

According to Morkham (2004) young people in residential care are there because of a range of acquired disabilities, from catastrophic accidents or unpredictable health events, or degenerative neurological diseases, such as muscular dystrophy. Further, the advances made in medical technologies and improved health care services allow people to survive injuries and unpredictable health events, as well increase the life span of people with degenerative neurological conditions. Subsequently, the number of people with acquired disabilities in Australia is growing (Morkham 2004, p 9).

Research on accommodation needs and preferences of young people

A confined review of literature on this topic revealed that only a small amount of documentation on this population group exists; in particular there is little to no information on their specific care needs or their participation in leisure or vocational activities. This view is supported by Winkler, Farnworth and Sloan (2006: 100) who argue that:

> *There is a critical absence of current information about people under 60 in residential aged care at both the national and state level, other than data on the overall number and proportion of permanent and respite care residents and admissions, by age and gender.*

This section briefly outlines studies that have been undertaken in this area and notes their main findings.

Surveys of nursing homes

Winkler et al (2006, p 101) cite two Australian studies which have surveyed nursing homes to describe the characteristics of younger residents. In 1995, Moylan, Dey and McAlpine conducted a national survey to provide an overview of people under 60 in nursing homes. They had a response rate of 68% (626 participants out of the 1515 residents under 60 in nursing homes) and collected information on age, sex, primary disability type, other significant disability types, cultural background, previous place of residence, Residential Classification Instrument score and additional support services received. The study found that the majority of residents under 60 had acquired brain injury as their primary disability

type and that very few younger people were relocated from an aged care facility to another accommodation option.

The second study was conducted by Cameron, Pirozzo and Tooth (cited in Winkler et al 2006, p 101) and focused specifically on people with acquired brain injury under 65 years residing in nursing homes. The study described the characteristics of these residents and concluded that, while many facilities were attempting to meet the needs of this group, they are simultaneously faced with limited resources, poor funding and inadequate training for this specialist area of care.

Young people living in aged care facilities in Victoria

Winkler et al's 2006 study into people living in aged care facilities in Victoria found that over one third of younger people in aged care were effectively excluded from life in the community and most younger residents are socially isolated and have limited opportunities for recreation. Their study concluded that placement of younger people in aged care facilities is inappropriate and alternative care models are required. Care models need to address the many complex care and clinical needs of this group such as challenging behaviour, pressure sore managements and PEG tube feeding. Furthermore, services need to be properly and adequately resourced to foster social contact and participation in recreation and community life (Winkler et al 2006, p 106).

In 2007, Winkler, Sloane and Calloway documented the needs and preferences of younger people with disability in Victoria, determining that the majority of younger residents sampled were 'effectively excluded from participating in community life' and had limited opportunity to make choices such as the time they go to bed or the content of meals. Sixty eight people of the 105 in the sample and their support networks indicated that they would like to explore alternate accommodation and support options, while 27 indicated they would prefer to stay resident in the current RAC facility. The preferences of ten people were unknown. Of those interested in moving, nine expressed a preference for a private residence; 56 would like to live in shared accommodation and three had a preference for other options.

Young people living in aged care facilities in Queensland

The Queensland Government produced a summary report on younger people with a disability based on a collaborative project between Disability Services Queensland and Queensland Health; this project investigated the needs of younger people with a disability living in aged care facilities. The report profiled 106 younger people living in residential aged care facilities through a review of their care plan, which was supplied by the aged care facility and the researchers also met with the younger persons, their significant other and facility staff. The key findings include:

- 74 people had high care needs and 32 had low care needs

- the majority had an acquired disability (68 people or 64.2%)

- the most common disability was acquired brain injury (37 people or 34.9%), followed by intellectual disability (18 people or 17%), cerebral palsy (13 people or 12.3 %) and Huntington's disease (9 people or 8.5%) (Disability Services Queensland and Queensland Health 2006: 8).

The project also involved stakeholder consultation with people living in aged care facilities, their families, aged care facility staff, Aged Care Assessment Teams (ACATs) and Disability Services Queensland regional directors. The consultations revealed that younger people entered such facilities generally due to a lack of alternative accommodation options in their community, following increasing or changing needs and the inability for their current care arrangements to continue (Disability Services Queensland and Queensland Health 2006, p 11).

Identified benefits for younger people in aged care facilities generally related to the level of physical care and support provided in these settings and that the person could remain near family if the facility was located close by. The negative outcomes related mainly to their social needs not being met due to experiencing boredom and not accessing relevant community activities or appropriate therapy services to meet their needs (Disability Services Queensland and Queensland Health 2006, p 11).

YPINH National Alliance Conference outcomes

The Young People in Nursing Homes (YPINH) National Alliance approached the Australian Government for funding for a Conference which was approved. The Conference was considered by the Australian Government and the YPINH National Alliance to be an opportunity to review progress of the COAG Younger People in Residential Aged Care initiative, in terms of what had been undertaken to date and actions which could help the Program in future to successfully deliver on its key objectives. As a result of the Conference, a number of recommendations for the future of the Program were identified:

- *Extending the initiative* – it was agreed that the initiative urgently needed to deliver more outcomes, more rapidly to be able to meet its five year targets. A number of cases for increased funding were made to enable improved responses and faster outcomes for consumers.

- *Funding* – calls were made for an end to the 'rationing' approach under the initiative that has seen funding delivered according to the numbers of consumers requiring a response rather than according to need.

- *Diversion from aged care* – there was strong support to increase the programs focus on preventing young people entering residential aged care through innovative programs that deliver timely and effective responses.

- *Declaration of an initial target of under 50s* – while the YPIRAC initiative was theoretically available to all younger people under the age of 65 years, the program's time and resource limits have resulted in the initial target group (<50) being the only group considered for participation. While the reasons behind inclusion of an age related initial target group are unknown, they may have included:

  - perceptions that this cohort's much smaller numbers increased the chances of success

  - mistaken assumptions that people over 50 were likely to enter or remain in aged care anyway

  - prejudicial thinking that locates individuals over 50 as 'less in need' of disability supports and services because they are approaching the 'aged' interface

  - financial and budgetary constraints regarding available funding for the initiative.

  Whatever the reason, the net result has been the exclusion of the over 50s cohort from the YPIRAC Program. In some States, eligibility has been so tightly defined that individuals must be under the age of 50 years as at 1 July 2006 to participate.

  Inclusion of an initial under 50s target group has thus served to reinvigorate one of the main areas of concern in the YPINH issue: a predominant service delivery methodology that provides services according to age not need.

- *An insurance-based approach to the future funding of disability services* – it was thought that this approach would deliver the lifetime support that this group needs and remove the need to ration services.

- *Rehabilitation* – there were unanimous calls across the stakeholder spectrum to include rehabilitation services in the initiative. There was also strong support for rehabilitation to be viewed as a 'lifelong approach' to skill development for recovery from injury and maintenance of health and wellbeing in the YPINH (young people in nursing homes) group.

- *Systemic reform with improved collaboration and integration* – there were calls for improved collaboration between government departments in health, disability, housing and aged care, especially in the design and implementation of innovative solution that maintain YPINH in the community; and in the delivery of services.

AIHW's final report on the YPIRAC 2007-08 Minimum Data Set

The AIHW's final report on the 2007-08 YPIRAC Minimum Data Set (MDS) summarised the characteristics of people who accepted services in 2006-07 and continued receipt the following year, as well as new clients in 2007-08. It also detailed the YPIRAC services received. The report defined a

YPIRAC service user as a person who has applied and been found eligible for the YPIRAC Program and has received one or more YPIRAC-specific services during the 2007-08 financial year period. These services include YPIRAC assessment and individual care planning, monitoring, alternative accommodation and support service package (AIHW 2009, p 2).

The final report on the 2007-08 MDS presented information on: the use of YPIRAC-specific services and support services; characteristics and service use of new and continuing service users; service use by the target population; and data processing and quality issues. These findings are reported throughout this mid-evaluation report.

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Appendix B   References

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