



YPIRAC²: the next steps.

Report to the Council of Australian Governments Standing Council on Community, Housing and Disability Services (SCCHDS)

**The Young People In Nursing Homes National Alliance
4 March 2011**

© Commonwealth of Australia 2011

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced by any process without prior written permission from the Commonwealth. Requests and inquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Attorney General's Department, National Circuit, Barton ACT 2600 or posted at <http://www.ag.gov.au/cca>.

The opinions, comments and/or analysis expressed in this document are those of the Young People in Nursing Homes National Alliance and do not necessarily represent the views of the Minister for Families, Housing, Community Services and Indigenous Affairs or the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, and cannot be taken in any way as expressions of Government policy.

Key recommendations

To build on the foundations YPIRAC¹ has established; to deliver strong multiple service area and programmatic involvement; and enable the effective provision of the suite of services YPINH require, YPIRAC² must

1. Maintain the three program objectives identified in YPIRAC¹
2. Use a risk management approach to assess need and deliver service responses
3. Include a Life time Care coordination model to provide a comprehensive cross program management capacity for the YPIRAC cohort. It should cover assessment, service design and oversee service delivery
4. Use specialist tertiary Care Coordinators to assess eligibility and support needs, manage the planning process, and oversee service delivery for YPIRAC² participants
5. Jurisdictions agree to work quickly to ensure YPINH become eligible for fully funded equipment, including high end pressure care, as part of State and Territory Aids and Equipment schemes
6. State and Territory Schemes are modified to include mechanisms that allow the rapid provision of, and upgrading of equipment for people with rapidly changing needs who may become YPIRAC targets.
7. Implement community based slow stream rehabilitation programs in all states
8. Develop discharge protocols that ensure rehabilitation is an inherent part of support packages for participants on exit from acute care
9. Develop protocols with aged care to ensure rehabilitation services can be delivered in aged care
10. Develop proactive partnerships with health re delivery of rehabilitation, nursing and allied health resources in the community
11. Develop partnerships with allied health, housing, families and disability agencies to deliver alternative supported accommodation options
12. On the basis that they know their members' needs better than anyone else, work with selected disability organisations on development of innovative support and accommodation solutions
13. In consultation with these organisations, develop a skilled workforce to support high and complex clinical and other needs in these community accommodation settings
14. Ensure that the Department of Health and Ageing is a core part of the structure of YPIRAC² to manage the involvement of State and Territory Health programs and the Aged Care system in the initiative's design and funding
15. Establish a cross portfolio working group to negotiate YPIRAC² as a 'joint venture' program to ensure it is not a disability only initiative
16. States and Territories Community and Disability Services Ministers must lead negotiations of cross program protocols around the YPIRAC² initiative with relevant portfolio areas within their jurisdiction as part of a national framework developed by the YPIRAC 2 initiative.

17. Develop a joined up assessment approach as a key partnership arrangement between health, disability and aged care.
18. Establish a national implementation and governance group and ensure that state and territory jurisdictions establish their own implementation and governance bodies
19. YPIRAC² must actively partner with jurisdictional housing programs (including such opportunities as the Federal Government's Supported Accommodation Innovation Fund) to deliver innovative capital development for the YPINH cohort through the program
20. Establish a COAG working party to
 - a. define and negotiate jurisdictional and program funding contributions
 - b. review funding amounts and allocations over the life of the initiative

Executive summary

YPIRAC¹ was the first truly national effort to tackle the YPINH issue. This report outlines the achievements of this introductory initiative; identifies where YPIRAC¹ was unable to have impact; and indicates what YPIRAC² must do to build on the foundations YPIRAC¹ has established.

It argues that complexity of need and the YPINH cohort's lifelong need for multiple service area involvement requires disability services to link with health, aged care and housing to deliver the suite of responses fundamental to the well being of this group.

It further argues that the development of a YPIRAC² that is focused as much on cross sector pathways as individual support, provides an opportunity to create an integrated, whole of government service response for high level disability services. This work can advance moves to embrace life time care approaches to service development and delivery that have been noted as an essential part of a future reformed disability services framework.

A model of program evolution has been used to describe the systemic reform imperatives that are relevant to the YPINH issue and to indicate that, as the next step in developing the service response for the YPINH cohort, YPIRAC² must

- Be characterised as a multi-program initiative, not simply as a disability services program
- Implement protocols around partnership with other arms of the service system to coordinate contributing responses from health, disability, aged care, housing
- Include growth funding for individualised services to be managed separately from general disability services
- Utilise a proactive, risk management approach, including a specialist case coordination model that can manage service plans and interventions across programs.
- Facilitate the creation of new service programs (slow stream rehabilitation and specialist case coordination) as well as program improvements in aids and equipment, capital development and sub-acute care.
- Include flexibility in planning and service design to account for changing needs and life circumstances.
- Incorporate a variety of service purchasing and delivery options including brokerage pools for meeting immediate needs; as well as individual packages that can be contributed to by other service areas.
- Strengthen existing COAG agreements to mandate existing service programs to deliver on YPIRAC priorities
- Include funding and in-kind contributions from other program partners of comprehensive cross program care to the YPINH cohort around
 - Assessment and review
 - Development of cross program service plans for each individual

- Negotiation with programs regarding their engagement with the service plan and the individual
- Provider management
- Liaison with individuals and families

In preparing this report, the Alliance has consulted widely with

- State community services and disability ministers
- Senior disability, aged care and health bureaucrats
- Disability, health and aged care service providers
- Rehabilitation program managers
- Aids and equipment program managers
- Consumers and families in all states and territories except the NT.

1. Introduction

Over the last 50 and more years, advances in medical technology and improved health care have delivered growing numbers of individuals with significant acquired disability and a range of clinical and other needs that are beyond the support capacity of the existing disability system. Their need for clinical interventions and sometimes, specialist nursing levels of care, means that in the absence of a system wide capacity to respond, nursing homes have been the default “answer” for these young people because of a presumed capacity to deliver 24 hour nursing care. Yet this is not the case.

The 2005 *Senate Inquiry into Quality and Equity in Aged Care* recognised this inadequacy and argued that, if younger people were placed in residential aged care (RAC), a way of assessing and funding their specific needs must be developed. The Inquiry’s Report stated:

The Committee recognises that in rare instances, a young person may choose to remain in an aged care facility. In such circumstances, the Committee recommends that the Commonwealth and the States and Territories work cooperatively to reach agreement on:

- *an assessment tool to address the complex care needs of young people in aged care facilities;*
- *mechanisms, including a funding formula, to provide rehabilitation and other disability-specific health and support services, including specialised equipment; and*
- *ways to ensure that the workforce in aged care facilities caring for young people has adequate training to meet their complex care needs.¹*

Despite the creation of the YPIRAC program to address the problem of young people in aged care, these specific recommendations were not able to be pursued through YPIRAC¹ with its focus on three target areas. They are, however, still relevant to the next phase of YPIRAC in that YPIRAC¹ worked in relative isolation from the aged care system; and cross-program assessment and funding approaches are still not in place.

Unlike the general population of people with a disability, people in the YPINH cohort with a degenerative condition or an acquired disability have either inherently unstable medical and support needs, or the need for timely and comprehensive rehabilitation supports.

In its proposal for national disability insurance arrangements, the Productivity Commission’s *Draft Report on Disability Care and Support* emphasises a number of

¹ Recommendation 26, Report of the Senate Inquiry into *Quality and Equity in Aged Care*,
YPIRAC², the next steps
Report to the COAG Standing Council on Community, Housing and Disability Services (SCCHDS)
Young People In Nursing Homes National Alliance
February 2011

key imperatives that align with the programmatic and funding reform the Alliance proposes for YPIRAC².

These include:

- need for high level policy development and cross sector protocols/agreements
- building the evidence base for long term care interventions,
- the importance of early intervention to prevent crises and avoidable poor outcomes
- infrastructure and workforce development, as the basis of a viable support service system.

These directions have also been identified in other pieces of work including the *Shut Out Report* and the *Continuous Care Pilots* in NSW and Victoria². In addressing these reform areas, YPIRAC² can ‘incubate’ some of these developments in the context of the YPINH complex care population. The joined-up service system (together with the development of new and improved service programs) that will support this group will be directly relevant to other areas of disability and the move to overall disability system reform.

The evaluation of YPIRAC² therefore becomes a major component of the initiative. This is not only to track the progress of the initiative itself, but to inform these wider reform discussions and prove the effectiveness of cross sector service pathways.

2. YPIRAC¹

YPIRAC¹ was never conceived as a solution but was intended as a starting point. It began from a low base of limited information and understanding of the YPINH cohort and had a primary focus on moving young people out of RAC. Its targetted KPIs failed to encourage systemic reforms and led to service responses that relied on ‘stand alone’ disability services, rather than the integrated outcomes that the YPINH cohort requires involving health, disability, housing and aged care.

YPIRAC¹'s funding was also insufficient to enable participation by those outside the ‘initial target group’. While the under 50s group has reduced over the term of YPIRAC¹'s operation, the continued growth of the over 50's cohort has merely underscored the need for YPIRAC¹'s targetted approach and dedicated funding stream to continue and expand in YPIRAC².

This view was reinforced in the AIHW's 2009 *Report into Australia's Welfare* which states that of almost 2000 young people who entered residential aged care in 2007-

² The MS Society ran Continuous Care Pilot programs in NSW and Victoria during YPIRAC¹ to test a combination intervention model to keep young people with progressive neurological conditions out of residential aged care. Both Pilots were independently evaluated. See: MS Society and Calvary Healthcare, *Evaluation of the Continuous Care Pilot' Victoria 2009*, and Disability Studies and Research Centre, UNSW, *Evaluation of the NSW Continuous Care Pilot*, 2010

08, close to 90% of admissions were aged between 50 and 64.³ This shows that while YPIRAC¹ was able to achieve a reduction in the under 50 group in residential aged care, this narrow targeting only addressed 10% of the cohort. In other words, to achieve the bottom line reduction in numbers of people under 65 in residential aged care, a systemic approach is needed.

Furthermore, most jurisdictions interpreted the program reference 'initial priority for those under 50 years of age' as an absolute eligibility criteria, and the Alliance is aware of a significant number of people who were refused access to support on age grounds and went on to be admitted to residential aged care. This is a stark example of literal attention to definitions and targets that warped the overall aims of the program. This was a particular issue for those people with disease related disability over 50 years of age who were not able to access any other relevant disability or equipment services to stay at home.

In essence, the person-by-person approach used in YPIRAC¹ was, while useful for those individuals who engaged with the initiative, unable to address the systemic causes of the YPINH problem. A systems driven YPIRAC² program with more sophisticated targets and incentives would avoid this type of implementation dilemma.

YPIRAC¹ has, however, delivered small improvements in capacity in the existing disability service system.⁴ Some new support and accommodation services have been developed; and some young people have been prevented from entering RAC. The clinical interventions this group requires have still not been integrated though, something highlighted in the program's mid-term review via reference to the particular needs of people with an ABI. The review stated that "Supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services..."⁵ and identified this linkage as "...a key challenge for the YIPRAC Program".⁶

The review also concurred that "...there is significant unmet need of YPIRAC, both in the under-50 target group, and particularly in 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."⁷

³ See AIHW, *Australia's Welfare 2009, the ninth biennial welfare report of the Australian Institute of Health and Welfare*, Canberra, 2009: 169.

⁴ A summary of YPIRAC¹'s key learnings is included in Appendix A.

⁵ urbis, *Younger People in Residential Aged Care (YPIRAC) Program, Mid-Term Review Report*.

Prepared for FaHCSIA by urbis, Sydney, 2009: 43

⁶ Ibid.

⁷ Australian Institute of Health and Welfare, *Residential aged care in Australia 2006 – 07*, June 2008, Canberra: iii

These findings support the case for designing YPIRAC² to include both a systemic reform component that creates pathways through various service areas; and substantial growth funding to meet individual needs across the entire YPINH population.

2.1. The next phase

While a key objective of YPIRAC¹ was to “enhance the delivery of specialist disability services”, YPIRAC² needs to extend this notion to include “enhance the delivery of specialist (to include clinical, rehabilitation, disability, equipment etc) services”.

This supports the findings from the mid-term review regarding the needs of YPIRAC to access supports from a range of government-funded programs and develops a sense of shared responsibility for YPIRAC. The development of access pathways to specialist supports must be formalised, and consideration must be given to the most effective ways to fund these additional specialist supports.

In fostering the beginnings of a more collaborative approach to service development and delivery between service arms and governments, YPIRAC¹ has delivered on its primary objective: to be a starting point. While the ‘how’ of delivering integrated responses is in its infancy, YPIRAC¹ has provided a substantial foundation and a clear indication that partnership and collaboration between service arms and jurisdictions is the way forward.

The challenge is to build on these beginnings over the next 5 years.

3. YPIRAC²

Where YPIRAC¹ demonstrated that management of the complexity and intensity of needs of this group is beyond the capacity of any one service system arm, YPIRAC² must incorporate strong funding and program collaboration through dedicated partnerships between health, disability, housing and aged care; and utilise a multifaceted risk management approach to service development and delivery.

As well as a useful outline of the process YPIRAC¹ began, Goldsmith’s description of the evolution of managed care⁸ indicates the future pathways that YPIRAC² and, potentially, YPIRAC³ must follow. To build on YPIRAC¹’s needs identification and target driven “responses for individuals “program, YPIRAC² needs to look to value improvement through policy partnerships, program linkages and targeted service development in addition to maintaining individual responses. From this aggregate point, YPIRAC³ should consolidate system wide reform and alignment, such that pathways and responsibilities are well defined and resources are available to meet the needs of the YPINH cohort.

⁸ Goldsmith, J.C “Managed Care comes of age”, in Bezold, C., Mayer, E. eds. *Future Care: responding to the demand for change*, Faulkner and Gray Inc., New York, 1996: 19-154.

In following this pathway, the YPIRAC initiatives are well placed to participate in and contribute to a number of national reform imperatives currently in play. These include the Health and Hospitals reform agreement⁹; aged care reform alluded to in the Productivity Commission's recent report on *Caring for Older Australians*¹⁰; and the Productivity Commission's forthcoming report on reform of the disability system¹¹.

YPIRAC² is therefore conceived as a dynamic intervention model based on risk management, joined up service responses and flexible resources. It has six strategic priority areas that follow the life time care management trajectory this group requires. These are

1. Lifetime care and support
2. Service development and improvement
3. Pathway linkages
4. Capital development
5. Individual support
6. Evaluation

3.1. Lifetime care and support

Given the nature of the disability types in the YPINH cohort, recognition needs to be given to the changing health and support needs of YPINH. They are effectively in an unpredictable pattern of long term transition. Transitions can involve deteriorating health and capacities with consequent increases in support requirements from various services areas. They can also include improvements in capacity as people recover from catastrophic injuries, or progressive diseases stabilise or go into remission.

The suite of health and disability support services required by individuals in the YPIRAC cohort has to be built around their social and clinical requirements and must be future focussed. Rehabilitation imperatives, disease prognosis, family situation and other life aspirations need to contribute to the overall plan.

Disability support components need to be flexible enough to match the changing needs of this group, and revisions to things like equipment prescription, medications and rehabilitation regimes require ongoing oversight from appropriately skilled coordinators.

⁹ See *A better deal for patients* at <http://www.pm.gov.au/press-office/better-deal-patients> Accessed February 15 2011

¹⁰ See *Caring for Older Australians, Key Points* at <http://www.pc.gov.au/projects/inquiry/aged-care/draft/key-points> Accessed February 15 2011.

¹¹ The *Disability Care and Support Draft Report* is due for release on February 28 at 1.30pm. See <http://www.pc.gov.au/projects/inquiry/disability-support>

Calvary Healthcare's submission to the Productivity Commission's *Inquiry into Disability Care and Support* declares that

High quality, responsive care can only be provided when there is a shared understanding of the client's goals and a framework which supports informed decisions, enables the implementation of plans and underpins the skill base of the relevant workforce. Health care and disability support need to work synergistically with the client and their family.¹²

While YPIRAC¹ used a comprehensive approach to assessment, it did not maintain programmatic attention to the clinical and social needs of the YPIRAC participants over the longer term. This requires a system that can draw down from multiple programs to deliver the standard of care outlined by Calvary above.

Clinical and other support services need to manage this dynamic, long term process by using a risk management methodology, actively managed through a care coordinator workforce.

The case management systems in Australia that were available to YPIRAC are generally limited in skill and scope, and are short term in nature. While the complex needs of the YPIRAC¹ participants may have been assessed utilising clinical personnel, the ongoing management of their care needs has been left to the generalist disability system.

While some case management services are competent in working with this population, it is not the industry standard, and many people in new YPIRAC services are not receiving the level of health oversight they need. This has created significant risks not only for them, but also for their service providers.

As it currently stands, the service definitions and industry practice of the disability system still does not have capacity to effectively manage the needs of this group across their life cycle. While YPIRAC¹ was initiated because the disability system could not service the YPINH group, it did not develop any new systemic approaches to increase its effectiveness in this area.

The cornerstone of an effective end-to end response for YPIRAC, including identification of people at risk and long term service coordination, is the development of a new lifetime care and support model. Such a model will enable cross program liaison and negotiation, and complement proposed inter-departmental protocols by coordinating service delivery from multiple programs and working closely across service arms.

¹² Mathers, S. Submission to the Productivity Commission's *Inquiry into Disability Care and Support*. Submission 46: 2.

3.1.1. Keeping young people out of Aged Care

While YPIRAC¹ worked across three target areas of diversion, service enhancement and moving to alternative accommodation, the main systemic gains in YPIRAC² are essentially in the area of providing sustainable alternative pathways and keeping young people out of nursing homes. That said, YPIRAC² still needs to improve the response to the stock of people already in aged care.

To do this effectively, we need those new program responses mentioned elsewhere in this report and additional funding for care packages and dedicated service coordination. While cross program protocols are an essential feature of YPIRAC², there needs to be a facility for coordinating these services at the participant level and ensuring that these protocols do not become a purely intellectual exercise.

The Continuous Care Pilots in both NSW and Victoria demonstrated an approach to managing the risk of aged care entry through skilled care coordination and a joined-up approach. Despite small cohorts, both pilots had high success rates and delivered sustainable community programs for a relatively low cost (\$20,000 per participant in Victoria, including some services). In NSW the Pilot was estimated to have offset nearly its total cost in prevented hospital admissions, in addition to delivering outcomes to its participants.¹³ Other outcomes from the CCP's are referred to in the following sections.

The Victorian *Slow to Recover Program* utilizes a similar approach to case coordination, planning and service articulation and has over time delivered similar diversion outcomes.

These models are able to be expanded and duplicated in all jurisdictions and YPIRAC² provides the context for putting them at the centre of the initiative. They provide a high value interface function across the existing disability and health sectors.

Dedicated resources for individual care packages need to be combined with these programmatic initiatives to enable a full response to the diversion objective.

3.1.2. Risk management

One of the reasons that the current case management system falls short of the mark for the YPINH group is that its service coordination modus operandi is not inherently forward looking. Taking the view that the YPINH population are in long term transition because of disabling disease processes or recovery from injury, a care coordination approach that is prospective and utilises a risk management methodology is more appropriate.

¹³ Disability Studies and Research Centre, UNSW, *NSW Continuous Care Pilot Evaluation*, Sydney, 2010: x.

The YPINH population face a range of risks to their health and independence, and require the service environment to be alive and responsive to these risks and transitions. If there is no capacity to identify and manage these risks then there is a higher likelihood of program failure, adverse health outcomes and escalating costs.

Attention to the value of a risk management approach was given by the evaluation of the Victorian and NSW Continuous Care Pilots. These projects aimed to better understand and manage the risk of aged care admission for people with progressive neurological conditions and trialled a comprehensive care coordination model.

Broadly speaking there were two main categories of risk identified by the CCPs in working to avoid inappropriate placement in residential aged care.

1. **Gradual impact risks** build up over time threatening the ability of the person, their family and the service system to maintain the person at home
2. **Immediate impact risks** present an immediate crisis that may cause a person not to be able to remain at home. In some cases these are the accumulated endpoint of gradual impact risks.

These are detailed in the following table:

Gradual impact risks	Immediate impact risks
<ul style="list-style-type: none"> • Carer stress • Funding and care provision not keeping up with needs • Failure to update equipment as requirements change • Cognitive issues leading to erratic decision making and a failure to persist with arrangements • Stress on relationships with care agencies • Weight gain • Financial difficulties • Complex family and children issues • Erosion of participants quality of life and emotional well-being 	<ul style="list-style-type: none"> • Health problems requiring hospitalisation • Pressure problems • Requirements for night time care, especially more than once per night • Health problems for the primary carer • Serious breakdown in relationships with care agencies

The Pilots adopted a risk management approach to identify short, medium and long term risks to an individual's health and well being. The evaluations identified that this approach was able to manage across social and clinical needs and resulted in improved outcomes for individuals.

Benefits included

- integral roles for individuals and families in planning and service delivery
- cost savings through amelioration of risk and associated cost blowouts
- improved efficiencies and effectiveness as the service system delivers proactively by identifying and delivering on identified risks
- improved collaboration, partnership and understanding across service sectors
- reduction in the impact of disease progression and anticipated appropriate increments to services that might accompany such progression
- support for individuals with progressive diseases and their families to become better informed about disease pathways and better able to address future planning issues as a result.

3.1.3. Active management through tertiary case coordination

As indicated previously, the suite of health and disability support services required by individuals in the YPIRAC cohort has to be built around their social and clinical requirements and must be future focussed. Rehabilitation imperatives, disease prognosis, family situation and other life aspirations need to contribute to the overall plan.

So too, disability support components need to be flexible enough to match the changing needs of this group, and revisions to things like equipment prescription, medications and rehabilitation regimes require ongoing oversight from appropriately skilled coordinators.

As the Victorian and NSW Continuous Care Pilots demonstrated, using specialist tertiary care coordinators to assess, deliver and manage service responses will deliver improved health outcomes as well as significant cost savings to the program.

These care coordinators will

- be a key liaison between health providers, participants and their families, providers and evaluators
- provide secondary consultancy for case managers and service providers to ensure successful implementation recommended interventions
- enable improved information flow, referral to services, identification of gaps, and the practical application of resources to ensure continuity of care and lifestyle.

Their work will involve

- Managing a small brokerage fund for each participant to deliver immediate responses if urgent need is identified.

- Developing and managing agreed service responses with participant and family, service providers and others with necessary input to deliver desired outcomes.
- Maintaining a 'watching brief' on service responses and be ready to activate more intensive involvement if required.
- Maintaining and managing all information and data pertinent to the participant and for those services developed and delivered through YPIRAC².
- Supporting design and delivery of innovative responses and providing reports on the net results of innovations to YPIRAC² and others as required.

Care coordinators will also have

- Authority to engage with all arms of the service system and develop partnered responses.
- A brief to develop and maintain effective networks in all arms of the service system and 'think outside the square' in delivering effective, timely and financially efficient service responses.
- Capacity to collaborate with all those with information pertinent to the health and well being of participants including acute care personnel, GP's, specialists, allied health professionals, service providers, advocates, member organisations, participant's family members and the participant him or herself.
- Capacity to recognise the need for innovative responses; collaborate in the design and delivery of innovative responses; and provide in depth reports on the net results of innovations to the scheme and others as required.

Recommendations

YPIRAC² must

1. Maintain the three program objectives identified in YPIRAC¹.
2. Use a risk management approach to assess need and deliver service responses
3. YPIRAC² must include a Life time Care coordination model to provide a comprehensive cross program management capacity for the YPIRAC cohort. It should cover assessment service design and oversee service delivery. Care coordinators will have mandated authority to engage with all arms of the service system and develop partnered responses around individuals. This will create the capacity to collaborate with all those with information pertinent to the health and well being of participants including acute care personnel, GP's, specialists, allied health professionals, service providers, advocates, participants and their families.
4. Use specialist tertiary Care Coordinators to assess eligibility and support needs, manage the planning process, and oversee service delivery for YPIRAC² participants.

3.2. Service system development

A significant shortcoming of the way YPIRAC¹ operated was that the major focus appeared to be on meeting the identified current needs of participants as per the targets, with no uniform methodology for dealing with the future needs of this group. Some of the gaps that emerged included ongoing access to clinical management, risk management and progressive provision of aids and equipment.

Waiting times for disability programs and aids and equipment were also problematic. While the dedicated funding of YPIRAC¹ did provide a solution to this, it did not influence the way funding is held or allocated in disability systems outside YPIRAC. The wait for services after needs assessment is in itself a risk factor for aged care or hospital admission. There are a range of new services required and improvements to existing arrangements in this area. From consultations by the Alliance, the key ones relevant to YPIRAC are as follows.

4.2.1 Aids and Equipment

Access to necessary aids, equipment and home modifications has been one of the more successful features of YPIRAC¹. The initiative was the only way younger people in aged care could get the customised equipment they needed and it gave more rapid access to equipment for those in the diversion group.

Diversions

From a risk management point of view for diversion candidates, equipment and home modifications are critical factors in keeping people at home. The Continuous Care Pilots examined the equipment issues faced by people with progressive neurological diseases in the YPIRAC target group. Their key risks can be precipitated by poor equipment responses to deal with the following problems:

- Primary carer and care services unable to safely transfer participant and/or complete care tasks (sometimes this has led to the threat to withdraw services)
- Pressure problems including lack of access to high end pressure equipment resulting in hospitalization and expensive (and lengthy) post acute care¹⁴
- Serious postural problems and associated pain and/or feeding difficulties
- Insomnia and related ill-health
- Lack of ability to leave the home.

One important risk factor is the rapidity with which equipment needs can change. Some clients required up to three revisions of wheelchair and

¹⁴ In 2001 it was estimated that \$350 million was spent on caring for patients with pressure ulcers, with the cost of each pressure ulcer estimated to be some \$61,000 and inpatient recovery time for a serious pressure ulcer measured in months or even years. See Australian Wound Management Association, *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*, Cambridge Publishing, West Leederville, WA, 2001.

equipment requirements in the life of the Continuous care project. If there are long delays in processing equipment requests and obtaining funding people are put at high risk of requiring residential admission due to pressure problems, inability of carers to cope with transfers and care tasks and/or pain.¹⁵

YPIRAC¹ was able to meet many of these needs for eligible people identified as being at risk of aged care admission. Many more carried this same risk but were excluded from YPIRAC¹ due to age or funding limits.

ABI Rehabilitation and support

For many people with an ABI, equipment forms a critical part of their recovery and prospects for rehabilitation. Combined with an absence of long term rehabilitation programs, ineligibility for aids and equipment if resident in aged care exacerbates their loss of potential and can contribute to further physical and psychological damage.

The NSW and Victorian CCP Pilots have demonstrated the benefits of early intervention and provision of appropriate aids and equipment. This is especially the case where investment in high end pressure care equipment has the potential to reduce hospital admissions, save millions of dollars in the process, to say nothing of improvement in health and well being for participants.

Eligibility

Different jurisdictions dealt with equipment purchase in different ways, but the fact that this service was available was a positive and necessary inclusion in YPIRAC¹. NSW funded the Enable scheme to the tune of \$4.1m to make the YPIRAC group eligible, while Victoria funded equipment and modifications through individual packages. Although using individual packages increases flexibility to some extent, a drawback of the Victorian approach is that data collection is more difficult.

One of the major disappointments of YPIRAC¹ was its inability to influence companion equipment schemes to include eligibility for the YPIRAC group across jurisdictions. NSW and Victoria both went through extensive redevelopment of their aids and equipment schemes without expanding eligibility to YPINH who were otherwise a priority for their disability programs through YPIRAC. Queensland, SA and WA still exclude people with disabilities who are residents in aged care facilities.

Only Tasmania has expanded eligibility for equipment for those in the YPINH target group who were unable to access the YPIRAC program.

Other than Tasmania, state jurisdictions clearly believe that the Commonwealth Department of Health and Ageing has a liability for the total equipment needs of

¹⁵ See MS Australia and Calvary Healthcare Bethlehem, *The Victorian Continuous Care Pilot – Final Report*, Melbourne, 2009: 64.

their younger nursing home residents with a disability. Strict attention to YPIRAC¹'s blunt targets and the fact that the availability of funding to address this need reduced the imperative to seek joint funding reform with the Department of Health and Ageing's Aged Care program, has likely resulted in this lack of reform initiative.

Aged care providers are committed to providing comprehensive care and support to their younger residents, but find they are often compromised due to their inability to access customised equipment. DoHA's Residential Care Manual makes the Aged Care subsidy's limits clear.

In regard to equipment, the subsidy paid to aged care providers covers physiotherapy assessment for equipment, continence equipment and basic equipment such as non-motorised wheelchairs for use within the facility. It does not cover the type of customised equipment usually required by younger people with disabilities with high and complex needs, such as electric wheelchairs, customised seating, a high end pressure mattress, communication aids or a tilt in space commode chair.

Rather than assuming that lack of provision of aids and equipment to younger residents in RAC is a deliberate cost shift from the States and Territories to the Commonwealth, it is more likely not to have been in anyone's interest to raise the issue. The resolution of this major gap is one reason for the inclusion of DoHA in YPIRAC².

The exclusion of young people in aged care from equipment programs has the effect of transferring significant risk to aged care providers who will manage clinically precarious situations without the means to provide essential customised equipment. If a younger resident is hospitalised as a consequence of an otherwise preventable skin breakdown or other adverse event, this risk and cost is transferred back to the State health system. Quite apart from the cost shifting implications, ultimately it is the younger residents who will suffer the health and quality of life impacts of living with acute and chronic unmet equipment needs.

The need to create a national equipment strategy and overhaul the current disjointed arrangements has been noted and recommended in a number of forums. Most recently the Health and Hospitals Commission and the National Aids and Equipment Reform Alliance have highlighted this under –recognised reform area.

While this overall reform is mostly outside the scope of this report, the National Aids and Equipment Working Party convened by FaHCSIA must address the funding and eligibility issues for young people in nursing homes as a key part of the YPIRAC² program.

Pressure care

Pressure care is a comparatively new area of expertise and is still not well understood or practiced. With extant aids and equipment programs delivering only

YPIRAC², the next steps

Report to the COAG Standing Council on Community, Housing and Disability Services (SCCHDS)

Young People In Nursing Homes National Alliance

February 2011

small funding amounts for basic pressure mattresses and other pressure equipment, the high end pressure equipment the YPINH cohort requires is usually out of reach.

Yet pressure ulcers have major impacts on those YPINH unable to move independently. They can become socially isolated as a result of having to spend long periods in hospital or bed; surgery or expensive vacuum treatment is sometimes required; and long-term complications are an ever-present risk.

In 2001 it was estimated that \$350 million was spent on caring for patients with pressure ulcers, with the cost of each pressure ulcer estimated to be some \$61,000¹⁶ and inpatient recovery time for a serious pressure ulcer measured in months or even years.

While not all pressure ulcers can be prevented, many are caused by inadequate equipment, notably seating and unsuitable pressure mattresses. Providing the correct pressure relieving equipment is not optional for the individual. Yet waiting times, lack of adequate resourcing and limits on types of products make it so.

If they are unable to get the right equipment, YPINH with pressure ulcers can spend up to 6 months in hospital recovering. Such a stay is extremely expensive in increased community care costs and nursing home burden upon discharge. It also places the individual at greater risk of consequent skin breakdown in an area that remains weakened as a result.

Investment in a high end pressure mattress, good seating, self-management support and staff competencies can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment.

Recommendations

1. Jurisdictions agree to work quickly to ensure YPINH become eligible for fully funded equipment, including high end pressure care, as part of State and Territory Aids and Equipment schemes
2. State and Territory Schemes are modified to include mechanisms that allow the rapid provision of, and upgrading of equipment for people with rapidly changing needs who may become YPIRAC targets.

3.2.1. Rehabilitation

Mainstream subacute health services (rehabilitation) do not utilise the kind of long-term models of care that the YPIRAC cohort need. Their approach is time limited and goal based, meaning that people with long term needs and unpredictable conditions are poorly served or excluded from much needed interventions. In both brain injury and neurological conditions, this adds extraordinary complications to care regimes,

¹⁶ Australian Wound Management Association, *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*, Cambridge Publishing, West Leederville, WA, 2001.

given that disability services and specialist rehabilitation services are not substitutable. Breakdowns in care can lead to preventable adverse health outcomes, and exclusion from accessing rehabilitation can be a direct cause of inappropriate aged care admission.

In fact, over 70 percent of admissions of younger people to aged care are from acute or sub-acute settings. Yet their ongoing rehabilitation needs are not captured by the current aged care assessment model, and the daily bed subsidy in no way allows for this rehabilitation to progress. While YPIRAC¹ was able to provide equipment and some lifestyle based service enhancement services, rehabilitation remains a major gap in the approach to the YPINH issue.

Targeted programs do, however, exist in some states that provide outreach rehabilitation and clinical services. These include the Victorian *Slow to Recover Acquired Brain Injury Program (STR)* and individual rehabilitation packages in WA. Programs like these need to be expanded and made routinely available to the YPIRAC cohort in every jurisdiction as component programs within the broader YPIRAC initiative.

YPIRAC² must have capacity for identification and comprehensive assessment of an individual's needs before discharge from acute care, so that a multifaceted rehabilitation support package can be available on referral to the next accommodation setting. Doing this means that where a person resides will not determine whether rehabilitation is provided or in what measure it is delivered.

As the Victorian STR program demonstrates, the transitional dynamics around this group means that a flexible, community based rehabilitation model is preferred to one that is based only on sub-acute facilities. Actively providing the rehabilitation services this group needs will deliver clear cost benefits by reducing their care costs over the long term. Such savings are indicated in a cost benefit analysis conducted by the Brightwater Care Group in regard to the planned redevelopment of its Oates Street Rehabilitation Service. The report declares that

It is relatively common to discuss rehabilitation in terms of the improvements to the quality of life of the people who receive it...However...purely from a narrow (and conservative) economic perspective, effective rehabilitation is valuable, due largely to its ability to reduce the cost of care for those with ABI. If we as a society propose to save the lives of those who acquire a traumatic brain injury, rehabilitation has not only a moral justification but is also a very real way in which costs can be saved within the health system.¹⁷

The report goes on to say that rehabilitation can reduce an individual's weekly care hours by between 35 and 91 hours per week, and deliver yearly cost savings of

¹⁷ ACIL Tasman, *Oates Street facility redevelopment: a cost benefit analysis*, Perth, 2010: vii. Forthcoming.

anywhere from \$158,522 for someone with high and complex needs, to \$78,390 for someone with low support needs.¹⁸

Recommendations

YPIRAC² must

1. Implement community based slow stream rehabilitation programs in all states
2. Develop discharge protocols that ensure rehabilitation is an inherent part of support packages for participants on exit from acute care
3. Develop protocols with aged care to ensure rehabilitation services can be delivered in aged care health
4. Develop proactive partnerships with health re delivery of rehabilitation, nursing and allied health resources in the community.

3.2.2. Innovative support and accommodation models

There was high expectation that YPIRAC¹ would start to address the system wide reforms that are needed to resolve YPINH issue including development of innovative support and accommodation models.

Despite actively preventing some young people entering RAC and delivering small improvements in disability service capacity through development of a small number of new supported accommodation services, YPIRAC¹ was unable to trial alternative pathways and service types. While the small growth in capacity YPIRAC¹ delivered was welcome, these new services have remained in the realm of group homes, often without the clinical input this group requires.

Innovative supported accommodation models already exist in many states, many expressly developed to support the needs of the YPINH group and incorporating clinical support services. These include

- shared on site support with individual unit accommodation (St Martin's Court, Melbourne)
- onsite support with family unit accommodation (Fern River, Perth)
- individual unit accommodation with shared on site support and community involvement (HOPES cooperative living project, Hobart)
- cluster shared houses with onsite support and rehabilitation (Dorothy Sales Cottages, Canberra) and
- 'salt and peppered' supported accommodation in high rise developments with onsite care (Cairo project, Melbourne, in development).

¹⁸ ACIL Tasman Op.Cit: 16.

YPIRAC² must develop and trial innovative supported accommodation options that respond to different levels of need, as well as the changing needs of this group, including

- Supported accommodation services that accommodate families as well as individuals
- Palliative care services that can provide family accommodation and support for individuals in end stage disease
- Inclusion of supported accommodation services in high rise developments
- Specialist supported accommodation services that support younger people with early onset dementias and other degenerative brain diseases such as Huntington's disease. These services to include capacity for family accommodation and support.

Recommendations

1. Develop partnerships with allied health, housing, families and disability agencies to deliver alternative supported accommodation options
2. On the basis that they know their members' needs better than anyone else, work with selected disability organisations on development of innovative support and accommodation solutions
3. In consultation with these organisations, develop a skilled workforce to support high and complex clinical and other needs in these community accommodation settings.

3.3. Pathway linkages

While a key objective of YPIRAC¹ was to "enhance the delivery of specialist disability services", YPIRAC² needs to extend this notion to include 'enhance the delivery of specialist services including clinical, rehabilitation, disability, equipment etc'.

This view is supported by the findings of the mid-term review regarding the needs of YPIRAC to access supports from a range of government-funded programs and develops a sense of shared responsibility for YPIRAC. The development of access pathways to specialist supports must be formalised through the negotiation of YPIRAC², and consideration must be given to the most effective ways to fund these additional specialist supports that do not rely on YPIRAC as an island program.

In many cases some rehabilitation and equipment services were funded through the diversion and enhancement packages in YPIRAC¹. While these clearly benefited the individual participants, it meant that YPIRAC¹ became an alternative funding source, albeit a non-sustainable one. This meant that there was no imperative to reform or develop the very programs YPIRAC was duplicating. It may be that these programs (such as sub-acute health or equipment schemes) were looking at YPIRAC as a trial.

However, as indicated above, there was no real change effected on these sectors by YPIRAC.

The need for dedicated pathways and service program partnerships emerged more strongly as YPIRAC¹ matured. Once the extent of the cohort's needs was established, it was clear that more than just disability services were required to actively change the service environment that caused young people to enter aged care.

As much as anything, the timing of services and the ability for services to be articulated are critical factors in keeping people out of aged care. The lack of any funding headroom in all disability programs (even with YPIRAC) and the adherence to the throughput model in healthcare, mean that deliberate steps need to be taken at the program level to establish pathways and co-funding models.

The YPINH issue has been characterized over time as one of cost shifting and buck-passing and this is still evident in the over-reliance on disability services programs to absorb an array of responsibilities for people with complex needs that these programs simply cannot deliver on their own. The renegotiation of YPIRAC² is a key opportunity to redefine the approach to this issue and establish aligned priorities and complementary funding arrangements with a range of service programs.

3.3.1. Protocols between funding programs

Utilising a joint venture approach for YPIRAC² means a range of formal protocols will need to be established to create shared interests and priorities. Some of these will be about interface arrangements, while others will need to be about commitments to new service establishment.

Disability Services is often seen as the junior partner in these types of agreements so a precondition to developing these pathways and protocols will be COAG endorsement of a new joined-up approach and a mandate to link the various Commonwealth/State Funding agreements. It must be said that the negotiations around YPIRAC² are happening in a very different 'reform' environment. As one example, there is much greater awareness of and focus on the need for lifetime care and whole of government responses, especially via the Productivity Commission's current investigation into reform of the disability system.

Much of the work developing these pathways and links will be at the State/Territory level. While the Department of Health and Ageing needs to be involved with aged care/disability interface and funding issues, the practical transitions from hospital to the community, accessing equipment, rehabilitation and disability services are all issues that can be resolved at this level. This will particularly be the case for those States/Territories who are party to the Aged Care reforms to make them fully responsible for services to people with disabilities under 65. The YPIRAC² initiative does however need to establish the framework, objectives and timetable for these agreements so they are transparent and nationally consistent.

A useful working model of such a joined-up approach is the Multiple and Complex Needs Initiative in Victoria (MACNI). Underpinned by legislation, the MACNI binds together a number of portfolio programs across mental health, justice and disability services. It has its own collaborative coordination methodology and care planning process. MACNI was designed as a collegiate response because the target group had a range of issues that could not be managed within one program area. A significant feature is that the collaboration model is defined, and it is clear where programs must deliver together and separately.¹⁹

Alongside MACNI, Victoria has also made efforts to develop formal protocols between its departments of health and disability for the YPINH population. While YPIRAC¹ may take some of the credit for fostering these beginnings, YPIRAC² needs to intensify and expand them further, a point underscored in discussions around future disability policy by Dr Jane Tracy.²⁰

3.3.2. Joined up assessment

Despite the need for joined up assessment approaches for YPINH being raised in both the 2005 *Senate Inquiry into Equity and Quality in Aged Care* and the 2006 *Senate Inquiry into the Operation of the Commonwealth State Territory Disability Agreement*, such approaches have not been implemented.

While YPIRAC¹ adopted specific assessment protocols²¹ once participants were identified as eligible, no amendments or enhancements have been made to the Aged Care Assessment process. Some States and Territory Disability programs initiated protocols with ACAT around a joint process for exhausting options in Disability Services before completing an ACAT assessment. However, given the pressure on attendant care and accommodation services with a capacity to support the YPINH group within Disability, anecdotal evidence is that this was more about formality than genuine partnership.

¹⁹ See <http://www.dhs.vic.gov.au/operations/multiple-and-complex-needs-unit> (Accessed February 24 2011). There has already been additional recognition of the need for some groups to have targeted health interventions. The Victorian Government's 2009 Disability Services Complex Health Needs Care Coordination Project explored improved healthcare provision to people with disabilities in Disability Accommodation Services houses and employed Care Coordinators with a nursing background to review and assess Health Plans.

²⁰ "Problems with service access arise when a person requires two or more service sectors to work together. Service systems have funding associated with areas of responsibility. Those areas of responsibility have boundaries and when a person's need crosses these boundaries there is a risk that issues of eligibility, communication and coordination result in vulnerable people 'falling through the cracks' and missing out on entitlements or, less commonly, experiencing confusing duplication and conflicting advice. Both situations result in suboptimal health outcomes." Tracy, J. "Achieving Equity in Healthcare Provision: A Health Action Plan", in Bigby, C. and Fyffe, C. (eds.) *State Disability Policy for the Next Ten Years - What Should it Look Like?*, La Trobe University, Bundoora, 2010: 87.

²¹ Both Queensland and Victoria appointed different community groups to undertake assessments for YPIRAC¹. Tasmania purchased the assessment tool developed for the Victorian program. All other jurisdictions used existing or in-house disability assessments to assess participants.

The process for admission of a young person into aged care is much the same as it was pre YPIRAC, with only a basic appreciation being gained about the needs of the individual. The ACAT assessment looks at a person's need vis a vis what the aged care system can deliver, rather than what the individual really needs, so much of the important detail about rehabilitation and equipment needs are not recorded. There is also a significant gap in overall care coordination. Once people have been identified eligible to participate in YPIRAC¹, they have received enhancement packages. Rarely, though, have these been for full scale rehabilitation and lifestyle recovery.

Given that YPIRAC² is to be a joined-up initiative, a key component will be a MACNI style assessment protocol that involves health, aged care and disability services. This assessment process must be linked to the lifetime care and support model so that the various inputs and longer term commitments from partner programs can be established and services designed and implemented.

3.3.3. Aged care as transition

Most young people enter RAC on exit from hospital while recovering from injury or exacerbation of illness.

Their needs for a modicum of nursing care at this point, as well as the disability service system's profound incapacity to provide the clinical service component required and respond in a timely manner, means that nursing homes have become the default "answer" for these young people because of their presumed capacity to deliver 24 hour nursing care. Yet, as this report has indicated previously, this is not the case.

Nursing homes are resourced to support frail older Australians in the end stages of life. Average stays for older people range from 6 months to 2 years. Minimum staffing levels do not exist in RAC and care is predominantly delivered by Personal Care Assistants (PCAs), not trained nurses. Their lower staffing levels and the fact that PCAs are trained to support the very different needs of frail older people means that RACs struggle to support younger people **on their own**.

With funding and program support from disability and health, however, RAC offers an opportunity to provide transitional support services as an interim response.

Delivering a transitional service would enable rehabilitation and other sub acute service delivery to be available; support continued recovery; and do so in a safe and supportive environment that can provide the nursing levels of care this group needs during this time. It would also provide the disability system with time to coordinate the supports, accommodation and resources needed to enable the younger person to return to life in the community in a safe and supported manner.

Using RAC as a transition option means that disability and health funding and program partnership would not 'stop at the door' as presently happens, but would accompany the younger person into RAC to deliver rehabilitation services; personal support (to top up RAC's contribution and ensure the younger person's more intense needs can be properly supported); aids and equipment (including high end pressure care); and community access.

As a transition option, a clear exit point would need to be agreed by all partners before entry to RAC; and ongoing monitoring and review would need to be in place also to manage changing health and other needs over the transition period, as well as ensuring exit to the community will be achieved in the agreed timeframe.

Partnering with RAC to deliver a transition option has obvious benefits for all partners. For health, provision of rehabilitation services and inclusion of disability partnered funding and care reduces the likelihood of recurrent admissions to acute care. For aged care, collaborative funding from disability to top up provision of personal support, program collaboration and contribution around aids and equipment and community access, as well as health's contribution around rehabilitation, alleviates the intense pressure on limited RAC resources, stops the bleeding of these resources away from their aged care clientele and ensures staff can attend to their aged clients as they expect and want to do.

For disability, partnering with RAC in this way provides a 'breathing space' in which coordinated service responses can be developed and community support and accommodation service options can be developed and delivered. It also means that because the individual's health and well being has been maintained at optimal levels, transition to the community can proceed smoothly and with a minimum of fuss.

Recasting aged care as a transitional accommodation option, while providing the full suite of services as described above, means case coordination and service provision will work within a goal set that includes a positive future. It also changes the way that the disability and health system interact with aged care.

If aged care is recognised as a partner providing accommodation services, referring people into aged care from either system would no longer be the end of the road for these sectors. Instead, aged care would have porous boundaries, with other programs complementing its base service provision with developmental and specialist services.

Enabling rehabilitation and recovery through this transitional service, positions YPINH well to take up alternative options as they become available, or pursue other choices including moving home with family with support. As we move towards a national care and support scheme where new service developments will intensify, preparations for the future need to be made. Rethinking the role of aged care places it in the middle of the service pathway, not at the end.

In this brave new future, enabling 'aged care as transition' means every YPINH is "in" the initiative. At a minimum they would receive lifetime care coordination, with equipment, clinical and disability support services being brought in as recommended by a comprehensive assessment. Making such a partnership available will deliver substantial cost savings downstream for aged care, health and disability services by maximising health and well being in the YPINH group.

But this shift is only possible if YPIRAC² develops as a shared initiative of the relevant program areas. Previously Aged Care has been reluctant to become involved in YPIRAC¹, believing it was the disability system's job to fix the YPINH issue. As we have described, and as the experience of YPIRAC¹ has shown, this complex issue requires more than one program to manage it. Aged Care must become a foundation partner in YPIRAC², and work cooperatively with FaHCSIA around a range of interface issues such as workforce, joint funding, standards and assessment. Aged Care also needs to do the same with health programs at State, Territory and National levels.

Improving the capability of the aged care system to manage younger people and ensuring that entering aged care is not a one-way ticket for a younger person is a critical change process that YPIRAC² must deliver.

Recommendations:

1. Ensure that the Department of Health and Ageing is a core part of the structure of YPIRAC² to manage the involvement of State and Territory Health programs and the Aged Care system in the initiative's design and funding.
2. Establish a cross portfolio working group to negotiate YPIRAC² as a 'joint venture' program to ensure it is not a disability only initiative
3. States and Territories Community and Disability Services Ministers must lead negotiations of cross program protocols around the YPIRAC² initiative with relevant portfolio areas within their jurisdiction
4. Develop a joined up assessment approach as a key partnership arrangement between health disability and aged care.

3.4. Capital development

As part of a coordinated, joined up service response, YPIRAC² must have access to sufficient capital to build support and accommodation capacity that addresses the particular needs of the YPINH group.

As this report has already indicated, the disability system is predicated on supporting individuals. Yet because of their acquired disabilities, many YPIRAC² participants are likely to be active parents, partners and family members. Having already lost their health, employment and other life opportunities, losing their family connections and involvement is something that not only adversely affects individuals' health and well

being but can deliver further imposts on the social welfare system as families struggle to stay intact.

YPIRAC² must partner with jurisdictional housing programs and encourage opportunities to develop supported accommodation options that can sustain family units; and enable YPINH to continue being active parents and partners to their loved ones.

To this point, capital development has been the only source for disability housing. Capital funding needs to be a strong part of YPIRAC² to enable new services to be developed. Without this, YPIRAC²'s pathways will become "dead end streets" as there will be no capacity to support individuals in the community.

Recommendation

YPIRAC² must actively partner with jurisdictional housing programs (including such opportunities as the Federal Government's Supported Accommodation Innovation Fund) to deliver innovative capital development for the YPINH cohort through the program.

3.5. Individual funding

Although YPIRAC¹'s design limited its scope to working to individual targets only, the individuals that were assisted derived significant benefit. Despite the numbers of people that needed YPIRAC assistance greatly overwhelming the program's capacity to deliver to no more than 10% of the YPINH cohort, there is no question that the demand for targeted assistance is present and growing.

As indicated elsewhere in this report, YPIRAC¹'s mid-term review concluded that "there is a body of quantitative and qualitative data to support the conclusion that the Program is having a very positive impact on young people with disabilities who either reside in, or are at risk of entering, RAC".²²

The review also identified the "... significant unmet need of YPIRAC, both in the under 50 target group, and particularly in 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."²³

It is imperative that YPIRAC² extends the quantum of funding for individual support as well as for the program areas mentioned earlier. As a joined-up, joint venture initiative, YPIRAC²'s individual packages can no longer include only basic disability services or be totally funded by Disability Services programs. They must be

²²urbis, *Younger People in Residential Aged Care (YPIRAC) Program, Mid-Term Review Report*.

Prepared for FaHCSIA by urbis, Sydney, 2009: 44.

²³ Australian Institute of Health and Welfare, *Residential aged care in Australia 2006 – 07*, Canberra, June 2008: iii.

constructed by drawing down from other program areas and coordinated by YPIRAC specialist care coordinators.

It is appropriate to concentrate individual packages on the three original target areas, with a particular priority given to diversion packages. YPINH still need the provision of packages of care to move out of aged care, and the enhancement packages still need to be delivered, but within a new context of aged care as transition services. This is explained in more detail in section 3.3.3.

Diversion, or prevention of aged care entry, has come through very clearly in the Alliance's consultations as a key goal of future work in this area. While assisting younger people to move out of aged care needs to remain one of YPIRAC²'s features, YPIRAC¹ demonstrated that it is much more difficult and expensive to move a person out of aged care than it is to prevent their entry.

The additional resources for aged care diversion delivered in YPIRAC¹ were highly effective. All jurisdictions exceeded their diversion targets, and a range of services were packaged up to enable people to remain at home or return to the community following extended hospitalisation.

While the decision to roll over the Commonwealth contribution of \$122m into the National Disability Agreement was a positive commitment, it will only sustain the new services created under YPIRAC¹ as they are and do nothing to address changing needs for this funded group over time.

For the gains made to be sustainable and for there to be a continued capacity to provide alternatives to aged care, an increased funding deal needs to be made within disability funding programs to provide increased numbers of individual care packages. As part of YPIRAC², targets should continue to be set for the numbers of individuals assisted under this part of the initiative.

Under such an approach, disability programs would contribute to packages for disability support services. Other programs would be required to make their own funded contributions to individual programs. Equipment, rehabilitation, community care or aged care accommodation are all services that need to be separately funded, but linked to the individual service program by the lifetime care and support coordinators.

3.6. Evaluation

One of YPIRAC¹'s biggest shortcomings was its lack of a comprehensive evaluation framework. This, combined with the instrumental design of the program has led to a very shallow data mine for this landmark initiative. While the mid term review looked at the target achievement, Victoria instigated a 'quality of life' evaluation

with a small number of program participants and NSW undertook its own programmatic evaluation,²⁴ there needed to be something far more organized.

It would have been extremely valuable to have conducted an implementation evaluation for YPIRAC¹ given the variance of methods and interpretations the different jurisdictions used to put the program into action, and the impact that these decisions and interpretations had on the conduct of the initiative.

It is absolutely imperative that an independent 5-year evaluation framework be put in place that can examine the full operation and impact of the initiative. Given the added complexity of the systemic program development in YPIRAC², it is important to have greater evaluation discipline this time around.

This should be done through a linked set of smaller projects utilising appropriate evaluation methodologies and staged reporting. The framework needs to include:

- Implementation of the initiative
- Target analysis
- Consumer and family experiences
- Health outcomes (including rates of hospitalization/rehospitalisation)
- Effectiveness of care coordination methodologies
- Costs and benefits
- Efficiency of jurisdictional processes
- Program creation and improvement
- Pathway development
- Effectiveness of governance arrangements
- Development and effectiveness of cross-program relationships/protocols
- Program alignment with reform programs

The AIHW's evaluation of the Disability/Aged Care Interface projects that were part of the Aged Care Innovative Pool, was a thorough examination of the costs, processes and benefits of the projects. This provided strong data and conclusions to inform later work in this area, and is the kind of approach that is recommended for the service development part of YPIRAC²⁵

The evaluation component has been included as a key strategic priority so as to build it in as a central feature. Program evaluation often is a second tier activity. However

²⁴ Both Reports are forthcoming.

²⁵ AIHW, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report*, Canberra 2006

in the context of the suite of related reform agendas on foot, it must be made a first order priority when designing YPIRAC².

4. Governance of YPIRAC²

The prevailing view that YPIRAC¹ was the province of disability services, in concert with the fact that the initiative itself was primarily run as an intergovernmental arrangement, meant that innovation was stifled. Families, consumers and advocates were not part of the response and despite disability services clear inability to support the YPINH cohort, state disability officials were left to implement the initiative from a 'business as usual' approach.

Because YPIRAC² is primarily about systemic reform this governance approach cannot be repeated. Instead, YPIRAC² must establish a national implementation and governance group that includes the Department of Health and Ageing, national peak bodies relevant to the target group including the Young People In Nursing Homes National Alliance, Spinal Cord Injury Australia, Brain Injury Australia, the Neurological Alliance of Australia, the Australasian Faculty of Rehabilitation Medicine, Aged and Community Services Australia, the Consumer Health Forum, as well as consumer and family representatives.

The States and Territories need to take a similar approach to ensure cross-program engagement at the implementation level. These would be similar in nature to the National Disability Insurance Scheme (NDIS) and National Injury Insurance Scheme (NIIS) Implementation Taskforces recommended in the Productivity Commission's Interim Report.²⁶

Recommendation:

Establish a national implementation and governance group and ensure that state and territory jurisdictions establish their own implementation and governance bodies.

5. Funding for YPIRAC²

The current state of active reform across jurisdictions, service areas and programs makes it difficult to identify particular funding pathways.

What is clear, however, is that taking a proactive approach to delivering the services and supports this group requires in a timely manner, does deliver significant cost savings to the service system. The Report of the NSW CCP is instructive in this regard, with the total cost of the program returned in reduced hospital admissions alone over the course of the pilot.

²⁶ Productivity Commission, *Disability Care and Support Draft Report*, Volume 2, section 17.4., Canberra, 2011.

As a joint venture program, however, it is obvious that each relevant jurisdiction must contribute money to a stand alone YPIRAC² Funding Pool.

Although its quantum was insufficient to the task, YPIRAC¹'s 50/50 split between federal and state jurisdictions worked well in delivering a discrete, partnered pool of funding to the initiative. A similar, but dramatically expanded funding allocation should be considered for YPIRAC², embodying funding contributions from state and federal jurisdictions.

This time, though, YPIRAC²'s funding should not be limited to jurisdictional allocations only but include programmatic funding contributions from health, aged care and housing, as well as disability, to provide additional funding and program growth. A brokerage pool must also be included as part of the overall funding consideration.

A COAG working party must be established to negotiate and allocate funding.

Recommendation

Establish a COAG working party to

- define and negotiate jurisdictional and program funding contributions
- review funding amounts and allocations over the life of the initiative.

SELECT BIBLIOGRAPHY

ACIL Tasman, *Oates Street facility redevelopment: a cost benefit analysis*, Perth, 2010. Forthcoming.

AIHW, *Australia's Welfare 2009, the ninth biennial welfare report of the Australian Institute of Health and Welfare*, AIHW, Canberra, 2009.

AIHW, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report*, Canberra 2006.

AIHW, *Residential aged care in Australia 2006 – 07*, Canberra, June 2008.

Australian Wound Management Association, *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*, Cambridge Publishing, West Leederville, WA, 2001.

Community Affairs References Committee *Quality and Equity in Aged Care*, Report of the Senate Inquiry into Aged Care, Parliament of Australia, Canberra, 2005.

Disability Studies and Research Centre, UNSW, *NSW Continuous Care Pilot Evaluation*, Sydney, 2010.

Goldsmith, J.C “Managed Care comes of age”, in Bezold, C., Mayer, E. eds. *Future Care: responding to the demand for change*, Faulkner and Gray Inc., New York, 1996: 19-154.

Mathers, S. Submission to the Productivity Commission’s *Inquiry into Disability Care and Support*. Submission 46: 2.

MS Australia and Calvary Healthcare Bethlehem, *The Victorian Continuous Care Pilot – Final Report*, Melbourne, 2009: 64.

Productivity Commission, *Caring for Older Australians, Draft Inquiry Report*, Canberra, January 2011.

Productivity Commission, *Disability Care and Support Draft Report*, Volumes 1 and 2, Canberra, 2011.

urbis, *Younger People in Residential Aged Care (YPIRAC) Program, Mid-Term Review Report*. Prepared for FaHCSIA by urbis, Sydney, 2009.

Tracy, J. “Achieving Equity in Healthcare Provision: A Health Action Plan”, in Bigby, C. and Fyffe, C. (eds.) *State Disability Policy for the Next Ten Years - What Should it Look Like?*, La Trobe University, Bundoora, 2010.

YPIRAC², the next steps
Report to the COAG Standing Council on Community, Housing and Disability Services (SCCHDS)
Young People In Nursing Homes National Alliance
February 2011

Online

A better deal for patients at <http://www.pm.gov.au/press-office/better-deal-patients>
Accessed February 15 2011

The *Disability Care and Support Draft Report* is due for release on February 28 at 1.30pm. See <http://www.pc.gov.au/projects/inquiry/disability-support>

APPENDIX A

Key characteristics of the YPINH cohort

- Acquired disabilities from catastrophic injuries including acquired brain injury (>50%); and progressive neurological diseases such as Multiple Sclerosis, Parkinson's and Huntington's Diseases²⁷
- High and complex support needs profile
- High and complex clinical support needs profile
- Need for on going nursing care and other clinical intervention in the community and on exit from acute care
- Need for 'transition' – time, resources, accommodation – between exit from acute care and eventual return to community life
- Intact families where individuals are often active parents to children
- Integral need for rehabilitation and habilitation services over the long term
- Vital importance of Aids and Equipment in maintaining health and well being including requirements for high end pressure care and equipment
- Their previously able bodied lives means YPINH do not identify as *dis*-abled and have very different expectations of and aspirations for the service system that include
- Access to supports required to recover from injury and exacerbation of illness in a timely and adequate fashion
- Assistance with home modifications to ensure continued and active presence within nuclear family
- Access to employment
- Support to recover as much of their previously able bodied life as possible
- Not living with other individuals with disabilities
- Assistance to remain within nuclear families and continue to be active parents and partners
- Need for ongoing individual advocacy in the absence of a care coordination response

²⁷ ABI was the primary disability group of close to half (46%) of all Younger People In Residential Aged Care (YPIRAC) service users in 2007–08. This compares with 4% of Commonwealth State Territory Agreement (CSTDA) service users with ABI as a primary disability group. Two in five YPIRAC service users (40%) had neurological disability with or without another type of disability. This compares with 13% of CSTDA service users with neurological disability. See AIHW, *Australia's Welfare 2009. 9th Biennial Welfare Report of the AIHW*, AIHW, Canberra, 2009: 169-172.

APPENDIX B

A brief summary of YPIRAC¹'s key learnings includes

- Clinical input is an integral part of service development and delivery for the YPINH cohort
- Aids and Equipment (Assistive Technologies) are fundamental health imperatives for this group
- Initial high end investment in Aids and Equipment, rehabilitation/habilitation, development of clinical and other support services et al, will pay dividends in decreased long term care costs over time
- Rehabilitation and habilitation services are a critical part of an integrated service response
- Using 'stand alone' disability services, cannot solve the fundamental issues of health management and rehabilitation for YPINH
- YPIRAC¹'s program funding was inadequate to the task of delivering on the program's 3 objectives. As a result, eligible over 50s were unable to participate
- YPIRAC¹'s primary focus on clearing aged care beds could not address or deliver systemic reforms required to finally resolve this issue
- Prevention (or diversion) should be the primary objective of future programs
- The absence of the Department of Health and Ageing from the initiative made the aged care system a 'target' of YPIRAC rather than a key partner
- While group homes may suit some, greater variety and innovation in support and accommodation options is required
- Program integration and genuine partnership between health, disability, aged care and housing is essential to deliver the integrated service responses required
- The disability system's focus on supporting individuals doubly disadvantages many YPINH who are active parents and partners in nuclear families. Future responses need to sustain and maintain family units
- Information and transparency is essential if partnerships between service arms and consumers are to be realised. Information needs to be widely available and the initiative promoted across the service system.
- Families must be directly involved in the development and delivery of care for loved ones
- Partnership and collaboration between service arms, jurisdictions, individuals, families and service providers is not only critical to delivery of the suite of service responses required by this group, but is an essential part of a life time care approach for the service system
- A proactive, risk management approach as utilised in the Victorian and NSW Continuous Care Pilots, provides a programmatically and economically viable base for a life time care approach
- YPIRAC¹'s use of KPIs compromised efforts to address systemic reforms and system collaborations. If KPIs are included in YPIRAC² they should be part of a broader evaluation and not be used as a way of forcing predetermined responses from disability services

- Entirely absent from YPIRAC¹, evaluation should have been active from the announcement of the initiative. Not having a substantive national evaluation component in YPIRAC¹ has meant lost opportunities to gather data and other important shared information; and deliver informed reform options
- Because YPINH require services from multiple arms of the service system, they should maintain multiple program eligibility. Doing so will deliver
 - flexibility,
 - efficiency in developing long term responses and
 - if each program contributes a part of the quantum required, the risk of a single program having to find the total quantum on its own, is reduced
 - Via a targetted approach and dedicated funding, YPIRAC² has the potential to 'road test' options to be delivered through a life time care approach; and develop the infrastructure that will be needed if the Productivity Commission recommends systemic moves to a life time care methodology by the service system

APPENDIX C

Case Studies

Melissa: 51 years, hypoxic brain injury from brain haemorrhage.

Despite making a good recovery, Melissa entered RAC from hospital because of her need to receive ongoing support in a residential setting and a lack of available community based support. This move was made without any rehabilitation or other treatment to manage limb contractures resulting from her brain injury.

The nursing home was unable to provide the physiotherapy Melissa required, and over time she experienced severe contractures in both hands and feet. These became so severe that her hands could not be opened, remaining in tightly curled fists.

Melissa's fingernails began growing through the palms of her hands and surgeons recommended amputation of both hands to manage infection and the intense pain she experienced.

In the end, tendons were severed to release the contractures and amputation avoided.

Melissa experienced chronic severe pain throughout this time and has been left with hands she cannot use. This is especially distressing as she continues to slowly recover function and may have been able to control an electric wheelchair eventually, had she retained use of her hands.

As it is, she is now more dependent than she should be and requires two people to assist with transfers and all aspects of personal care - including eating, something the nursing home she lives in struggles to resource.

Had Melissa been able to access recommended rehabilitation services in RAC and medical interventions, such as Botox[®] injections to relieve her contractures, this appalling situation may have been avoided and Melissa eventually able to return to her family in the community.

At this stage and because her needs have significantly increased because of the absence of the therapies she needed, it is likely she will remain in RAC with attendant increased costs to deliver the care she now needs.

Stephen, 38 years. Multiple Sclerosis

Stephen was placed in hospital to manage an episode of disease exacerbation. By the time his health had stabilised, Stephen's needs had progressed to a point where he was unable to return home. He had difficulty swallowing and was PEG fed. His

continence was managed by an indwelling catheter and his limited movement placed him at high risk of pressure ulcers.

Stephen left hospital to live in a new group home, a community based service developed under YPIRAC¹. With previous expertise in supporting individuals with intellectual disability, the service provider concerned was ill prepared to support Stephen and made no provision in its service design for clinical services to support the individuals with progressive neurological diseases (PND) who would be living there. The service's support workers also received no additional training in the different needs of the individuals they would be supporting.

The day after Stephen moved in, his mother contacted the MS Society to say she could not find a support worker in the house to attend to Stephen. The Society sent one of its own staff to the house to support Stephen and to speak to the service manager about better attending to his needs. The Society also offered to train the home's support workers in the particular needs of those with PND and to work with the provider to ensure the supports needed were in place and maintained. This offer was not taken up by the service provider or Disability Services.

Over the next few weeks, things had not improved and Stephen's mother was regularly called to the house to assist with managing Stephen's PEG feeds, including setting up and monitoring the feed itself. His mother eventually went to the group home daily to provide Stephen's PEG feeds herself in an effort to make sure they were provided correctly. When his mother was unable to attend and staff attempted to manage matters themselves, the PEG became dislodged and an ambulance needed to be called.

The result was that instead of living in the community with the supports he needed to maintain his health and well being, Stephen spent most of the next several months being transferred to hospital by ambulance. After a hospital admission and stabilisation of his needs, he would return to the group home – until the next emergency. Over this time, the inadequacy of his care and the resultant stress these episodes introduced caused Stephen's health to deteriorate further.

After yet another hospital admission for issues with his PEG as well as a urinary tract infection and a sacral pressure ulcer, the service provider informed Stephen he could not return to his home and refused to support him further. Stephen was left in hospital with nowhere to go.

Over the time he had lived in the group home, the inadequacy of his care and the resultant stress these episodes introduced because he did not get the clinical and other supports he needed, caused Stephen's health to deteriorate dramatically. By the time the provider refused to support him further, Stephen was very ill indeed.

He was transferred to a local hospital and never returned to the community. Stephen remained living in hospital until he died, 2 months later.

While Stephen's death cannot only be attributed to a lack of necessary clinical supports and services available to him in the community, his workers' inability to support him adequately and the constant round of hospital admissions he had to deal with would certainly have compromised his health over the longer term.

The lack of case coordination and clinical service input; the poor training of support workers and the provider's lack of understanding of the suite of supports and services required for the YPINH cohort meant that costs consequently incurred by Health and Disability Services were much greater than they needed to be. The cost to Stephen and his family was immeasurable.

Julia: 24 years, diagnosis of extremely rare form of dopamine responsive dystonia.

Incorrectly diagnosed at birth with cerebral palsy, Julia was born prematurely with left side Hemiparesis, but was able to walk, run, ride and swim like other children.

At around 17 years of age, Julia's physical condition began deteriorating to the stage where she was unable to sit up without support and she became dependent on others for her care. After a severe episode when she was 23 years, Julia was admitted to hospital and a month later had stabilised enough to return home.

Doctors have struggled to diagnose Julia's condition and despite walking in to hospital, she is now a functional quadriplegic with use of one finger on one hand only. Her prognosis remains unclear. She is now dependent on others for all her needs.

Julia has lived at home with her parents and sister all her life. She has had a minimal support package (5 hrs per week) from disability services previously.

Her family has provided all her care previously and after lengthy delays and obfuscation from the state's Aids and Equipment program, have now adapted their home to accommodate Julia's wheelchair themselves and done so for a fraction of the cost the A&E program would have charged.

Despite her family's agitation to bring Julia home and the hospital's desire to have Julia leave acute care, disability case management services did not activate until 7 months after Julia had been admitted to hospital. Throughout Julia's time in hospital, it has been left to her family to try to manage the situation and find an acceptable outcome.

By her 8th month in hospital, Julia had been approved for a \$100,000 disability support package from State Disability Services to provide support 5 days per week and some respite for her parents. Under the package, her family would provide

Julia's support on weekends to keep costs down. 2 months later, however, she was still in hospital because Disability Services says it does not have the funds to provide the package.

After Julia's story appeared in the media, Julia was offered a place in a new 6 person group home developed under YPIRAC¹ but managed by a service provider whose expertise is with people with intellectual disability. Julia and her family have several concerns as a result. These include

- Julia's compatibility with other residents. This has not been considered and she has no idea who the other residents will be.
- The level of support to be provided and the expertise of the support workers who will support Julia. This has not been identified.
- Clear concerns about the provider's lack of expertise in supporting people with high and complex clinical and other needs.
- The group home's capacity to support Julia's ongoing rehabilitation and other clinical needs
- The lack of adequate case coordination to manage the linkages between health and disability services required to maintain Julia's well being.
- Transport and access to rehabilitation, acute care and other allied health and clinical services
- Capacity to support Julia's work with young people through the *Reach Foundation*

The wastage of health dollars in this case is obvious. By the time she moved to the community, Julia had lived in hospital for 54 weeks. The cost of Julia's 12 months plus in hospital with acute care effectively providing disability accommodation, has already far exceeded the \$100,000 package she needs. Her continued residence in acute care means blockage of a bed needed by someone who is ill. The financial cost to the hospital is also intense. Because it receives a lower bed fee for every day she remains there, the daily bed day fee the hospital is receiving is already well below the cost the hospital incurs in providing Julia's care.

As Stephen's story illustrates, if the new disability service has inadequate understanding of Julia's needs and is unable to support her appropriately, Julia is likely to return to acute care and start a merry-go-round of moves between acute care and the group home. The cost to both disability and health could be avoided if appropriate care coordination was introduced to support the new service provider, ensure the supports and services Julia needs are in place and maintain those linkages between health and disability that will be needed to maintain Julia's health and well being.

Rebecca (Bec), 30 years. Progressive multiple sclerosis

Kindergarten teacher Rebecca was 28 years of age when she was diagnosed with MS after being admitted to hospital. Mother to a daughter, 4 years, and a son 6 months, Rebecca's husband is a horticulturalist in a senior management role.

After her diagnosis, Rebecca left the hospital with only a hired chair and a toilet chair to assist her at home. She received no information about disability support services or other clinical supports she may have been able to access.

Once home and because she had no supports, her health deteriorated and she found herself totally dependent on her husband for her personal care and support. Rebecca was unable to care for her children in any way and over the coming months was hospitalised many times. She says “No one came out and checked on me to see if I was managing and a bad situation got much worse.”

Rebecca was refused access to her State Government’s Home Modifications program on the erroneous grounds that her deterioration meant it was unlikely that she would remain at home. As the modifications were, in fact, essential to her remaining at home and continuing to parent her children, Rebecca spent her early accessed Superannuation payout on widening the hallway to her children’s bedrooms and building an accessible bathroom.

During one of her hospitalisations, she was put in touch with the NSW Continuous Care Pilot case coordinator. The case coordinator recognised the significant risks Rebecca’s diagnosis and situation carried, not only to her health and well being but to the stability of her family and her husband’s capacity to keep his job. The CCP’s Clinical Advisory Group worked to ensure the right clinical and other supports were put in place for Rebecca.

In the 18 months before she was enrolled in the CCP, Rebecca had been admitted to hospital 11 times for a total of 64 days. This was in addition to 3 weeks in a rehabilitation ward, 17 days in ambulatory care and 2 weeks respite instead of a hospital admission and does not count the countless visits to GPs and other specialists. Her husband was forced to take 2 months leave without pay and returned to work reduced hours in order to support his wife.

Because of this, Rebecca and her family had trouble meeting their mortgage payments. This led the state aids and equipment program to again refuse to undertake home modifications on the basis that Rebecca and her husband were likely to lose their house, despite being told by doctors that undertaking these modifications were a matter of urgency. When Rebecca requested Home and Community Care support she was told that this support would only be available to assist her and not to help undertake her parenting responsibilities such as preparing meals for her children.

Ultimately, a number of support programs refused to support Rebecca because they thought she would not remain living in the community. The fact that their refusal to assist her actually put Rebecca at greater risk of being placed in RAC, did not seem to be considered.

With the case coordination the CCP introduced, a risk management assessment was undertaken and the clinical and other supports Rebecca needed were put in place and managed. Since this time Rebecca has not been hospitalised, her health has stabilised and the stress her marriage was under has eased.

The CCP's proactive risk management approach and case coordination paid dividends in increased health and well being for Rebecca; and reduced the stress her family had been under trying to manage the impact of her disease themselves. Overall, the cost of the program was returned in participants reduced hospital admissions alone and the Alliance is aware of at least another 12 individuals in the same area who could have been referred to the program had it continued.

James: 24 years, ABI from motor vehicle accident.

Following his accident, James spent 8 months in hospital undergoing rehabilitation. During this time he made significant and rapid gains and was well on the way to recovering most of his function.

At the end of this period, the hospital decided he should be moved and James was sent to a nursing home.

He was placed in RAC because of his need for nursing care to maintain his recovery but without access to any rehabilitation or other much needed ancillary services.

6 years later, James remains in the nursing home but in a state of dramatically diminished capacity.

The lack of ongoing rehabilitation to support his continued recovery has resulted in deterioration of James' physical and emotional well being to the point where his condition is now worse than it was when he was first injured.

Despite the best efforts of the nursing home - something James' mother readily and gratefully acknowledges - James experiences increased pain and contractures, has developed pressure sores because of a lack of customised equipment (including a high end pressure mattress) and has become isolated and depressed due to his circumstances and lack of contact with his family and social networks.

It will now take intensive - and expensive - effort to assist James to regain the function and capacities he has lost since moving to the nursing home. Had he been able to continue his rehabilitation in the nursing home and been able to access the customised equipment he needed, it is highly likely James would have continued to regain function sufficiently to live in the community.

As it is, his clinical needs have increased and it is likely he will remain in RAC for the foreseeable future, delivering increased costs for his care and support as his function

continues to deteriorate.

Colin: 55 years of age, primary progressive Multiple Sclerosis

Colin has been in a nursing home in outer Eastern Melbourne for the past 3 years. He currently requires nursing care for most ADLs. He lives in a shared room with only a curtain separating him from the other occupant. Currently the bed is empty but the last person that shared the room regularly went through Colin's belongings when he was not in the room.

He has a laptop computer that sits on an over bed tray as there is no room for a desk or workstation, and the internet is his main form of contact with people outside the facility. To create a useable space for his computer, his bed has been moved in front of the bathroom door in his room and needs to be moved by staff for him to enter the bathroom. He is visited weekly by his 83 year old mother.

He moved to the facility directly from a rehabilitation centre. On arrival he bought a second hand electric wheelchair from another resident with his own money which fitted him and was suitable for his needs. The increase in his disability (including postural change) due to his primary progressive disease has resulted in the wheelchair becoming unsafe for Colin. He is frequently sliding out of the chair and is on a lean while sitting in it. It has no leg supports, meaning he has been damaging his legs on the doors due to his uncontrollable spasms and lack of padding on the chair. The massage service provided by the facility stopped late last year, and his level of discomfort has increased as a consequence. He developed a sacral pressure sore in early 2009 that could no longer be managed by the facility and was hospitalised for 2 weeks in January this year.

The chair is uncomfortable and unsafe, and the need for a new one was identified 15 months ago. He is still using this chair as it is his only way of getting around.

The search for a new wheelchair has been difficult. The fitted chair he needs costs \$12,000, a figure beyond Colin or his provider. As Colin was not eligible for his equipment through the Victorian Aids and Equipment Program, Colin's therapist exhausted 8 funding options before finally having an individual Support Package approved by Victorian Disability Services following significant lobbying. Although the funding has been approved the chair is yet to be delivered.

Following his hospitalisation he has been receiving treatment through the Hospital in the Home program with vacuum pump and dressings. A nurse visits Colin 2-3 times per week to change the dressing, a procedure that takes around an hour and is extremely painful. While this treatment is not a financial burden on the facility, the additional care and supervision required around transfers and monitoring takes additional time.

The vacuum dressing procedure is highly effective, but is also very costly. In addition to the hospital stay, the treatment is likely to cost in the vicinity of \$40,000 (incorporating the cost of the vacuum pump, foam dressings and nursing time) to heal the ulcer. The treatment is likely to be at least a 3-month episode and is disruptive and painful.

This episode could have been avoided with the timely prescription of a customised wheelchair early in 2009. There was no available funding source and the provider had no means to provide the right equipment out of the daily bed subsidy. In order to avoid paying \$12,000 for the clinically appropriate wheelchair, around \$50,000 has been spent by the health system, and hours of therapy time displaced into fundraising and submission writing. This is not only a case of indefensible cost shifting, it has caused major deleterious health and quality of life impacts for Colin.

He has at least another 6 weeks of treatment in store, by which time his new chair should be delivered.