



**Joint Submission  
to the Department of Health and Ageing's  
Review of the Aged Care Funding  
Instrument**

*Young People In Nursing Homes National Alliance, MS Australia and  
Brain Injury Australia  
March 2010*

## Key Recommendations

- 1 DOHA consider implementing an individualised assessment and funding scheme in addition to the ACFI funding level to be implemented in for younger residents with high and complex needs that include the general domains of:
  - Rehabilitation
  - Aids and Equipment
  - Social and Community Involvement
  - Care and Support
- 2 With urgency and priority, DOHA a) fund the cost of customised equipment for younger residents to close the funding gap and reduce the risks to providers and residents, and b) initiate discussions with FAHCSIA and the States and Territories on the development of a sustainable cross-jurisdictional funding scheme for aids and equipment.
- 3 DOHA join with FAHCSIA and the States and Territories to establish cross program policy and operational links to ensure that systemic barriers and cross jurisdictional issues identified by the YPIRAC program can be resolved
- 4 DOHA examines the options for a) delivering rehabilitation services to younger residents and b) introducing funding and program links with State and Territory health and disability programs to ensure that younger residents are able to access essential rehabilitation and transitional services while they reside in aged care
- 5 DOHA work with the Aged Care Sector and the YPIRAC services to support the development of a training and education regime for the aged care workforce focusing on strategies for working with younger residents
- 6 DOHA make younger residents a priority group for their Community Visitors Scheme
- 7 DOHA must be an active partner in the next phase of the YPIRAC initiative's design and implementation

## 1. Introduction: young Australians with disability in residential aged care

The **Young People in Nursing Homes National Alliance**, **MS Australia** and **Brain Injury Australia** welcome the opportunity to contribute to the Aged Care Funding Instrument Review.

Some 6800 young Australians with disability presently occupy a not insignificant 5% of residential aged care beds nationally. Data received from providers indicate the majority of younger residents receive RCS level 1-4 subsidies.<sup>1</sup>

These young people are largely individuals with acquired disabilities and high and complex clinical and support needs. They have entered RAC for a variety of reasons including the need for nursing level care following catastrophic injury; exacerbation of progressive neurological disease requiring an episodic approach to facility based nursing care<sup>2</sup>; and the inability of the disability service system to respond to their level of need in a timely manner. Along with these main groups are numbers of people with very diverse presentations, often with few of their needs in common, and from widely varying age groups.

Recent studies have concluded that

[YPINH] have high levels of complex health conditions which require daily care and a range of specialist expertise and equipment...accommodation services need to develop strategies and supports to integrate management of these complex health requirements.<sup>3</sup>

Previous studies indicate that the population breakdown of young people in aged care with acquired disabilities is

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|--------------------------------------|------------------|
| ▪ <i>Acquired Brain Injury (ABI)</i> | 30%              |
| ▪ <i>Physical Disability</i>         | 27%              |
| ▪ <i>Neurological</i>                | 23%              |
| ▪ <i>Intellectual/psychiatric</i>    | 20% <sup>4</sup> |

These figures also include a large number of people with high needs without speech who are particularly at risk.

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<sup>1</sup> Of a total 6,505 residents under 65 in June 2006, the majority or 4,911, were categorised as high dependency (RCS 1-4); the remainder or 1,594 were considered low dependency (RCS 5-8). *Source*: AIHW analysis of DoHA Aged and Community Care Management Information System (ACCMIS) database. Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4<sup>th</sup> Edition, Canberra, 2007: 135.

<sup>2</sup> It remains a fact that solutions have been more readily found when people have been compensated, and an individualised approach implemented.

<sup>3</sup> Winkler, D., Sloan, S. and Calloway, L. *Younger People In Residential Aged Care. Support needs, preferences and future directions*, Summer Foundation for the Victorian Department of Human Services, Melbourne, 2007: 26.

<sup>4</sup> See *The ABI Strategic Plan*, Victorian Department of Human Services, Melbourne, 2001.

ABI was also the primary disability group of close to half (46%) of all YPIRAC service users in 2007–08. This compares with 4% of 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.<sup>5</sup>

The poor representation of this group within disability services shows the service gap that exists and underscores the responsibility the aged care system has in meeting the needs of younger people in its care.

While there has been a slight trend downwards in the proportion of younger people as a proportion of the entire residential aged care population, the raw numbers continue to grow. Despite the efforts of the Council Of Australian Governments Young People in Residential Aged Care program, it appears that people under 65 will remain a significant group in nursing homes (currently 5%) and as such, the aged care funding and standards regime must respond comprehensively to their needs.

### **1.1. Limitations of the Aged Care Funding Regime with regard to younger people in RAC**

Entry into the aged care system for young people is via the Aged Care Assessment Service and a policy determining that people under 65 are eligible to enter the aged care system. Beyond this statement and assessment process, the entire Act and DoHA policy frameworks are silent on the particular expectations and care regime needed for young people.

Because the Aged Care Act is prescriptive, things that are not stated in the Act are not acted upon. Standards, provider approvals, policies, practices and workforce management, can ignore many of the needs of young people who can spend much of their adult life in nursing homes.

Yet it has become a practical reality that younger people will continue to reside in RAC because of

- the inability of disability services to deliver nursing levels of care to residents with clinical and complex support needs
- demand issues in state disability services
- intensifying pressure on acute care beds
- geographical considerations and
- the sheer force of timing demands between the competing interests of health and disability programs.

These practical contingencies mean that the Aged Care Funding Instrument (ACFI) needs to acknowledge that younger residents are within its compass; that they are

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<sup>5</sup> AIHW, *Australia's Welfare 2009. 9<sup>th</sup> Biennial Welfare Report of the AIHW*, AIHW, Canberra, 2009: 169-172.

poorly served by its current scope; and that, in many cases, they are damaged by its current limitations.

Aged care is often the overflow safety net for the community in regard to unmet need for accommodation services. Aged care has become the de facto disability accommodation provider over the years and a reluctant and ill-equipped one at that. These circumstances mean that the ACFI needs to ensure adequate care is funded and provided; and that aged care standards reflect this role.

Because of their presence in aged care, the Commonwealth has a responsibility to provide increased service levels and targeted standards through the Act for the YPINH cohort.

## 1.2. Recognition of the differing needs of YPINH in RAC

*Despite making a good recovery from a brain haemorrhage, Melissa entered RAC because of her clinical needs but without any ongoing rehabilitation or other treatment to manage limb contractures resulting from her brain injury. As a result, 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.<sup>6</sup>*

In his 2004 *Review of Pricing Arrangements in Residential Aged Care*, Professor Warren Hogan noted that the YPINH problem was significant, and a poor outcome for all stakeholders.

The needs of the younger disabled residents are not being met as fully as they might be ...Provider resources are being stretched and the Australian Government is funding residential aged care beds which are not being occupied by the target population, that is, the frail aged... The Review considers that no disabled person should be disadvantaged as a result of their residential status in an aged care facility.<sup>7</sup>

The Review supported an audit of younger people in nursing homes "...to measure the number, characteristics, age, disability types, assessed care and support needs, and geographical location of younger people with disabilities living in residential aged care."<sup>8</sup>

In its subsequent *Inquiry into Quality and Equity in Aged Care* (2005), the Senate's Standing Committee on Community Affairs agreed with this view but went further. One of its significant recommendations was to develop a way of assessing and funding the specific needs of younger people. The Committee stated its view thus:

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<sup>6</sup> See full case study: 20.

<sup>7</sup> Hogan, W. *Investing in Australia's Aged Care, Review of Pricing Arrangements in Residential Aged Care*, Department of Health and Ageing, Canberra, 2004: s 13.2.3.

<sup>8</sup> Ibid.

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.<sup>9</sup>

The conclusion of two separate Commonwealth inquiries into the position of YPINH in RAC has thus been to severally acknowledge the continuing presence of younger Australians in residential aged care; and recommend conclusive action be taken to address – and resource – their differing needs.

Failure to enact the Senate Committee's recommendation particularly, will continue to place residential aged care providers in a position of risk relative to their provision of care; deliver diminished health and well being to the YPINH cohort; and, because of this, cede greatly increased costs to the health and aged care service system.

### **1.3. COAG YPIRAC initiative**

In recent years, and through the Council Of Australian Governments (COAG) establishing and implementing the Younger People In Residential Aged Care (YPIRAC) initiative, the focus on young people living in aged care has been on creating alternative, community based services; and improving the lives of those younger residents remaining in nursing homes.

However and despite the creation of the YPIRAC program to address the problem of young people in aged care, the recommendations mentioned above have not been addressed.

The response of the YPIRAC program to people living in aged care has been limited in size and scope. It has relied on ad-hoc assessment protocols across states and has only delivered a response to those residents less than 50 years of age.

For those outside the scope of the program, the problem is as intense as it ever was, and there has been very little attention given to these issues within the aged care policy environment. The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has worked closely with the States and Territories on implementing the YPIRAC program and there has been cross sector collaboration at a provider level. As the Commonwealth authority responsible for YPINH, it would have

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<sup>9</sup> Community Affairs References Committee, *Report of the Senate Inquiry into Quality and Equity in Aged Care*, Commonwealth of Australia, Canberra, 2005: xix

been beneficial for the Department of Health and Ageing (DoHA) to have been much more closely involved in its progress.

As the following figures from the Australian Institute of Health and Welfare (AIHW) indicate, the YPIRAC program has managed to address only 10% of the total number of YPINH in RAC.

- Almost 2,000 younger people entered residential aged care in 2007–08 as permanent residents; close to 90% of these new admissions were aged between 50 and 64 (The YPIRAC program primarily targets people under 50!)
- These differences may reflect a traditional CSTDA service model geared around people with intellectual and psychiatric disability, many of whom are highly mobile. Before the YPIRAC program, the specialist disability system was clearly not meeting the needs of many people with complex nursing needs and limited mobility, as can be caused by ABI or multiple sclerosis, for example<sup>10</sup>

The YPIRAC initiative has had some good successes with individuals and in developing some new services. However, its biggest constraint has been the severe under funding allocated to it by the COAG and the fact that it had no capacity for the state disability implementers to create cross program links with health and aged care. This remains a major imperative going forward.

Despite its intentions, the COAG YPIRAC program has thus far failed to respond to a large cohort of young people with significant unmet need who live permanently in residential aged care. For various reasons, including diminished health and inability to return to the community, this group will not be assisted by the YPIRAC program and, due to unresolved program interface issues with disability services, have no prospect of having these needs properly met.

## **2. The issue: unmet need**

The issue for younger people in residential aged care is that they are located in inappropriate settings with inadequate services to address their needs. While individual aged care providers do their best to deliver quality care to their younger residents in spite of the funding and other shortfalls they confront, the difficulties providers face in caring for a single younger person or a small cluster of 2 or 3 cannot be underestimated. Their impact is felt in the following areas.

### **2.1. Health management for YPINH**

Staffing levels in residential aged care are set to cater for the very different needs of the predominantly frail elderly population these facilities are designed to accommodate. YPINH have diverse and more intensive care needs to those of older residents and care regimes around younger people with complex healthcare and

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<sup>10</sup> AIHW, *Australia's Welfare 2009, 9<sup>th</sup> Biennial Welfare Report of the AIHW*, AIHW, Canberra, 2009: 169-172.

disability support needs is often much more demanding in time and intensity for RAC staff.

Younger residents present with a number of significant health issues that providers have to manage with limited resources. The following table details the health issues reported in a study of 105 RAC residents under 50 in Victoria undertaken by the Summer Foundation.<sup>11</sup>

**Table 1: Health issues identified**

<b>Health issue</b>	
<b>Heart and circulation</b>	
Heart or blood pressure problems	19%
Limb swelling	20%
<b>Swallowing, eating or drinking</b>	
Swallowing difficulties	42%
Saliva management	20%
Problems with appetite regulation	16%
Special dietary needs	33%
Weight problems	42%
<b>Breathing</b>	
Recurrent chest infection	18%
Difficulty coughing, clearing secretions or sputum	14%
Altered muscle tone, spasticity or muscle spasm	59%
<b>Muscles and Bones</b>	
Contractures	31%
Involuntary movements	33%
Paralysis, loss of movement of arms or legs	32%
Osteoporosis	17%
<b>Pain</b>	
Fatigue	43%
Chronic pain problems	30%
<b>Skin Problems</b>	
Pressure areas or pressure care	31%

<sup>11</sup> Winkler et al, 2007: 26.

Skin rashes	38%
<b>Bladder</b>	
Urinary incontinence	69%
Urinary tract infections	23%
<b>Bowel</b>	
Faecal incontinence	47%
Diarrhoea or Colitis	54%
<b>Other</b>	
Epilepsy or seizures	29%
Sleep disturbance	12%
Arousal problems	9%
Diabetes – non-insulin dependent	11%
Diabetes – insulin dependent	8%
Thyroid problems	5%
Shunt inserted	8%
Dysreflexia/Dysautonomia	3%

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As this table demonstrates, younger residents with ABI or progressive neurological conditions require a more comprehensive service model to support individuals in the management of their disease; or their rehabilitation associated health needs. In addition to the physical health issues identified, residents with two or more mental health problems comprised 35% of the same cohort.<sup>13</sup>

Younger residents routinely require the support of specialist clinical and allied health professionals. This expert clinical and allied health input would include education and support by these professionals for aged care workers regarding medical management and clinical care and would include the following disciplines: nursing, physiotherapy, occupational therapy, clinical psychology, exercise physiology, social work, planning support and neuropsychological, speech pathology, dietician, counselling, behaviour consultancy, psychiatry and community access workers.

The value in such an approach through its capacity to maintain the health and function of younger residents and consequently reduce the burden of care for aged care staff, is illustrated in the following example. Residents who are continent are often left to use continence pads because nursing home staff do not have the time or resources to assist a younger person to use a toilet. As a result, younger people who enter RAC with continence often lose this important skill over time, something that places them

<sup>12</sup> Winkler et al, 2007: 26.

<sup>13</sup> Winkler et al, 2007: 31

at increased risk of skin breakdown and the advent of pressure sores. Loss of this skill may also compromise a younger person's capacity to relocate to community living if a supported service becomes available. Intensive resourcing is then required to regain a skill that need not have been lost if adequate education and funding to support maintenance of this skill had been available.

Similarly, anecdotal evidence exists of younger residents with diminished swallow reflex due to injury or exacerbation of illness, being placed on enteral feed regimes (including percutaneous endoscopic gastrostomy or PEG feeds) because staffing levels and time constraints mean nursing home staff do not have the capacity and time needed to assist a younger person to consume a meal.

Not only does the younger person lose the pleasure of tasting and eating real food; their swallow reflex can deteriorate further due to lack of use and they are placed at increased risk of complications associated with such invasive interventions including infection and reflux leading to often fatal pneumonias.

As well as diminished quality of life for the younger person, increased health and aged care costs are inevitable when the proactive resourcing that could have prevented this is not made available.

## **2.2. Responsiveness to changing needs and preventing avoidable deterioration**

Most YPINH enter RAC requiring continued rehabilitation to recover from injury or exacerbation of illness. Nearly all require allied health interventions to maintain skills regained and health and well being overall.

Without access to these vital services, YPINH experience severely diminished health and well being outcomes with often catastrophic results as the case studies provided in this submission demonstrate.

By virtue of the fact that they are receiving residential care in the aged care sector, YPINH are unable to access disability funded services, despite being part of the disability target group. Yet disability services expects RAC to provide all relevant services required by the younger person, including equipment, therapy and attendant care requirements.

The fact is that once a young person enters aged care, they are practically unable to access the rehabilitation they need to recover or improve. Nor are they able to access the equipment they require or access the community in ways that promote health and wellbeing with the result that YPINH are left to languish in RAC facilities. Yet with the right support, they would enjoy improved health and lessen the burden aged care providers face at present.

Without a stronger commitment to respond to changing needs, YPINH consumers will continue to not have their needs adequately met. The false economy involved in

under-servicing needs for assistance in these areas, will ensure continued deterioration that can only result in a blow out of the financial and human costs to government, consumers, their families and the community over time.

At present, there is no capacity for the health or disability system to properly assess need, and the current aged care assessment and funding calculation only utilises a very basic care needs analysis to establish care requirements.

A properly defined and resourced funding instrument needs to pick up the following four service domains, over and above the fundamental care requirements that are currently assessed. These four areas are

- Aids and Equipment
- Rehabilitation/Habilitation
- Social and Community Involvement
- Care and Support

### **2.2.1. Aids and Equipment**

*Colin 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 the wheelchair became 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.<sup>14</sup>*

One of the key gaps in assessment and service provision for younger people in aged care is aids and equipment. Residency in aged care facilities renders a person ineligible for State and Territory Aids and Equipment schemes, meaning that residents are forced to manage with inadequate equipment, risking adverse health outcomes like pain and skin breakdown.

The DoHA Residential Care Manual makes the limits of the Aged Care subsidy 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 electric wheelchairs, customised seating, a high end pressure mattress, communication aids or a tilt in space commode chair.

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<sup>14</sup> See full case study: 21-22

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. This 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 health system. Quite apart from the cost shifting implications, it is the younger residents who ultimately suffer the health and quality of life impacts of living with acute and chronic unmet equipment needs.

The YPIRAC initiative was mandated to overcome the buck-passing of responsibility for the young people in nursing homes group that had sadly characterised the issue over the last decade. Since its implementation in 2006, evidence about the importance of equipment to enable young people in nursing homes to engage with their communities and deliver basic safety and quality of life has been confirmed.

The direct funding of customised equipment for young people under 50 in aged care in Victoria by the *my future my choice* program, has delivered significant positive outcomes and has been one of the initiative's stand-out successes. It is one of a number of activities that has made *my future my choice* the leading State/Territory program in the YPIRAC initiative nationally.

While this funding model is highly effective in meeting the needs of young people in aged care, it is exclusive and unsustainable. It is only available to people under 50 years of age and can only continue as long as the *future my choice* program exists in its current form.

#### **2.2.1.1. Pressure care**

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 \$61,000<sup>15</sup> 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

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<sup>15</sup> Australian Wound Management Association, *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*, Cambridge Publishing, West Leederville, WA, 2001.

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.

The purchase of 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.

### 2.2.2. Rehabilitation/Habilitation

Following his car 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.

James 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.<sup>16</sup>

Rehabilitation is fundamental to the health and well being of every younger person living in RAC. As well as rehabilitation to recover from catastrophic injuries resulting in ABI, spinal cord and other impairments; and exacerbation of progressive diseases resulting in diminished capacity, younger people need ongoing allied health habilitation services to maintain and sustain function and well.<sup>17</sup> Currently seen as an 'optional extra', the YPINH cohort is condemned to a life of pain, dependency and impairment without this axiomatic resource.

Over 70 percent of admissions of younger people to aged care are from acute or sub-acute settings, and in the case of people with an acquired brain injury there are urgent rehabilitation imperatives that are not captured by the current aged care assessment model, and the daily bed subsidy in no way allows for this rehabilitation to progress.

At present, therapy services paid for out of bed subsidies are severely rationed across all residents and are nowhere near enough to meet the more intensive needs of a younger person. As well as denying capacity to recover, failure to provide access to these often life saving services results in a blow out of support costs for the younger person, diminished health with a consequent increase in acute care costs and increased risk to aged care providers who have a duty of care to these young people.

<sup>16</sup> See full case study: 21.

<sup>17</sup> Habilitation, meaning to become and remain fit.

In other words, younger people suffer catastrophic consequences by not accessing these services including acute pain, extensive and crippling contractures, social isolation and mental health and behaviour challenges

Cost effective delivery of rehabilitation services into RAC has already been demonstrated by the Victorian *Acquired Brain Injury Slow To Recover* program (STR), a slow stream rehabilitation program for Victorians with ABI that is the only program of its type in the country. This unique program is delivered to clients in their place of residence, whether that be hospital, home or RAC. Indeed, in the 2004 *Review of the STR Program's impact*, the Review Report states:

Without the program it is fair to surmise that a significant proportion of the target group would be inappropriately residing in aged care residential facilities or, inappropriately staying for extended periods in acute hospitals. The program has improved the quality of life of these people in that many are now living in more age appropriate surroundings and have the opportunity through slow stream rehabilitation to achieve greater independence and engagement with the community.<sup>18</sup>

The Report continues:

The implementation of the program has resulted in more effective and efficient use of limited relatively expensive resources in the acute system. A reduction in cost to the residential care sector has also been anecdotally reported, arising from the number of people now residing at home. In addition, any reduced disability at an individual level, has an impact on the long-term costs of care and quality of life.<sup>19</sup>

Despite the evident success of the STR program in the facilitating recovery of younger people with ABI in nursing homes; the reduction in long term costs to acute and aged care services the program delivers; and its capacity to move younger people out of RAC, rehabilitations services of this type continue to be denied to the YPINH cohort.

Some people in Victoria do have access to the *ABI Slow to Recover* Program that funds rehabilitation to clients with ABI in nursing homes. However, this is exceptional and is not available to the majority of young people with an ABI in RAC, or in aged care with other conditions.

This type of individually targeted rehabilitation is what many YPINH need through an enhanced aged care funding system as recommended.

### **2.2.3. Social and Community Involvement**

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<sup>18</sup> HDG Consulting Group, *Acquired Brain Injury Slow to Recover Program Review Final Report*, Victorian Department of Human Services, Melbourne, November 2004: ii

<sup>19</sup> Ibid

Social contact with family and friends is crucial to the social and emotional well being of any young person, and is particularly so for YPINH who – both geographically and emotionally – often live away from their social networks and have limited opportunities to engage socially with others.

Yet nursing homes are not funded to provide the community access that YPINH would benefit from. Their friends find it difficult to maintain relationships with YPINH living in aged care, and friendships tend to fall away and cease with time. Social contact tends to diminish as a result and severe depression and a consequent deterioration in health is the outcome.

Because they live in federally funded and managed accommodation, YPINH have no access to state based disability funds, services or equipment that could facilitate contact with friends and family either away from the nursing home, or within a broader program of community access. This, and the fact that they are living with older residents generationally removed from them, means that YPINH experience significant social and emotional isolation that adversely impacts their physical and emotional well being. This generational difference is declared in the fact that the majority of permanent residents in aged care nursing homes in June 2006, were aged 75 years or over (87%). Half of these were aged 85 and over and 7% were aged 95 years and over.<sup>20</sup>

One of the most pervasive problems for a young person living in a nursing home is social isolation. The Summer Foundation study into young residents found a major set of unmet social and emotional needs in the under 50 year old group in aged care.

- 53% received a visit from a friend less often than once per year
- 23% were visited by a relative on most days
- 11% received a visit from a relative less often than once per year

and in regard to participation in recreational activities:

- 30% participated in recreation activities organised by the RAC facility less often than once per month
- 32 people seldom or never participated in shopping or leisure activities outside the RAC facility  
13% of participants seldom or never went outside (e.g. into the garden of the RAC facility)<sup>21</sup>

This social isolation and boredom can contribute to mental health issues as well as challenging behaviours. The in-house activities in facilities often have little relevance and interest for younger people, and many do not share communal meal spaces with older residents.

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<sup>20</sup> As of June 30 2006, the majority of permanent residents were aged 75 years and over (87%); 53% were aged 85 years and over, and 7% were 95 years and over. The proportion of permanent residents who were aged 80 years and over increased from 64% in 1998–99 to 71% in 2005–06. AIHW, *Older Australia at a Glance, 4<sup>th</sup> Edition, 2007*, Australian Institute of Health and Welfare, Canberra: 134.

<sup>21</sup> Winkler et al, 2007: 25-38.

Individual residents require assistance and support in a number of ways to stay connected to their communities and families and maintain any association to the roles they have in life of a husband / wife/ father/ mother/citizen. This cannot be done without resources additional to the basic daily subsidy.

While Diversional Therapists in facilities are often the people who take responsibility for the general welfare of younger people, time and resource demands mean they are constrained in the design and delivery of effective options for YPINH. What is usually required to accompany any input from the DT is individual care hours and transport to physically get the person out into the community. But this is rarely available.

The needs across the younger group are to maintain relationships and connections prior to the onset of their disability and, for people with ABI in particular, regaining and relearning social skills and a positive self image is a very important component of their rehabilitation.

In many cases trips out of the facility are limited to medical appointments, which can hardly be classified as recreation.

A social and leisure plan needs to be established with each resident and funded appropriately.

#### **2.2.4. Care and Support**

In order to meet the whole of life care and support needs of a younger person in RAC, an individualise approach is required. The quantum and intensity of supports required by the YPINH cohort is clearly vastly different to those of older residents and requires comprehensive planning and delivery.

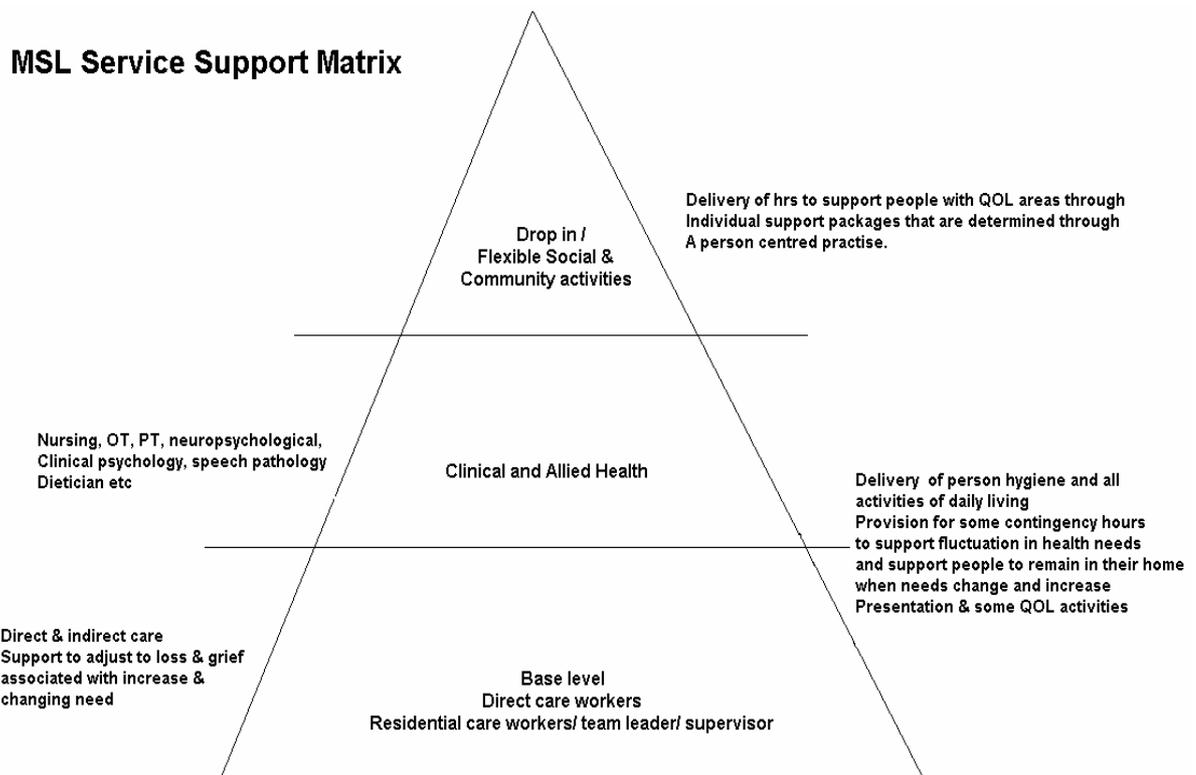
The most effective solution is to implement a specialised planning and individualised funding mechanism on top of the ACFI to capture individual needs across the four domains (rehabilitation, recreation and leisure, aids and equipment, care and support) and fund their delivery.

The ACFI is not designed to capture the whole of life needs of younger residents, and is not adequate on its own in this context. While the ACFI may be appropriate to identifying the basic daily care needs of a younger person, it will, however, miss the important elements needed to ensure a high quality service response in an aged care facility.

There is no capacity in the aged care system to develop or manage a long term individual plan with goals that may include moving out at a future date. This is a significant gap in the management of younger people in aged care and one that cannot be filled without funding from the aged care system to deliver the required supports.

DOHA must initiate the development of these tools and a funding source as they are primarily responsible - and liable - for these residents.

To effectively deliver services to younger people, the following model represents the sum of components to care design and delivery. This approach allows the whole person to be taken into account, and facilitates planning and delivery of responses that are not routinely considered for younger people in aged care facilities due to systems and resource constraints.



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<sup>22</sup> MS Australia ACT/NSW/VIC, *MSL Accommodation Planning Model*, Unpublished.

### **3. Conclusion: Residential aged care as transitional services for young Australians with disability**

As this submission has indicated, the YPINH group are largely those with acquired disabilities and high and complex clinical and support needs. Most enter RAC on exit from hospital while recovering from injury or exacerbation of illness. In other words, it is no longer tenable to assume that the needs of younger residents are the same as their older cohabitants. Nor that they can be adequately supported with existing aged care funding models.

Their need for a modicum of nursing care at this point; as well as the disability service system's profound incapacity to respond to individuals who arrive without warning and in need of an intensive response, means that RAC offers an opportunity to provide transitional support services as an interim response. In this regard, DoHA must have intimate involvement in the YPIRAC initiative's design and implementation going forward.

Delivering a transitional service would enable rehabilitation and other sub acute service delivery to be available; supports continued recovery; and do so in a safe and supportive environment that can deliver the nursing levels of care this group needs during this time. As the YPIRAC program matures and as Australia moves towards a life time care and support scheme nationally, there will be greater capacity in the future to develop appropriate community based services for this group.

Until this becomes a reality, the aged care system must 'step up to the plate' and ensure that every resident in its care receives services appropriate to their needs. Doing so requires adequate funding support that is presently unavailable through the existing ACFI. Making this funding support available will deliver substantial cost savings downstream for aged care, health and disability services by maximising health and well being in the YPINH group.

#### 4. Case Studies

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

Despite making a good recovery, Melissa entered RAC because of her clinical needs but without any ongoing rehabilitation or other treatment to manage limb contractures resulting from her brain injury. As a result, 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 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<sup>®</sup> 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 been increased through 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.

**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 is currently nursing care for most ADL's. 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 the wheelchair became 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.

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