Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

6 February 2015

Dear Ian

Re: Submission to the Senate's Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

I have pleasure in providing the Young People In Nursing Homes National Alliance's submission to this important Inquiry to you.

As a national peak, the Alliance has had the opportunity to work with young people living in residential aged care settings and their families; and partner with aged care, health and disability services to develop and support delivery of the integrated service responses these young people need.

Included in this email with our submission, are copies of three of the Alliance's policy papers that have relevance for the Committee's deliberations.

The first is a policy discussion paper on the need for *Cross Sector Service Coordination*. The second is a copy of the *YPIRAC^2: the next steps* Report we prepared for the COAG's Standing Council on Community, Housing and Disability Services (SCCHDS). The third is the Alliance's recently launched housing policy discussion paper, *Shaping the Future Today*. I'd be grateful if copies of these documents could be made available to members of the Committee.

I would also appreciate the opportunity to appear before the Committee at its hearings in Sydney to provide further evidence related to our submission.

Please don't hesitate to contact me if further information or clarification is required.

I look forward to hearing from you.

Yours sincerely

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YOUNG PEOPLE IN NURSING HOMES NATIONAL ALLIANCE
shaping the future today

Senate Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

Submission by the
Young People In Nursing Homes National Alliance

February 2015

Key recommendations

Recommendation One
That a joint taskforce be established across disability and aged care portfolios to address the chronic program incompatibilities between the aged care and disability programs regarding:

1. Co-funding arrangements
2. Provision of aids and equipment
3. Impact of co-payments and bonds
4. Service standards
5. Workforce issues

This taskforce must include consumer and sector representation, and representatives from the housing portfolio.

Recommendation Two
That COAG mandate and invest in the development of integrated care and support pathways using cross sector collaboration between health, housing, disability (including the National Disability Insurance Scheme (NDIS) and aged care programs as a key part of the NDIS transition.

Recommendation Three
Jurisdictions agree to work quickly to ensure Young People In Nursing Homes (YPINH™) become eligible for fully funded equipment as part of all State and Territory Aids and Equipment schemes.

Recommendation Four
As a matter of priority, the National Disability Insurance Scheme develop a comprehensive 'plan of action' with regard to YPINH and development of the services and pathways this cohort requires to participate effectively in the Scheme.

Recommendation Five
That the Australian Government Department of Health facilitate engagement with health programs and key professional and consumer bodies to develop and implement a national rehabilitation strategy, including a framework for the delivery of slow stream rehabilitation programs in all jurisdictions.

Recommendation Six
That the Australian Government Department of Health facilitate work to be led by health programs to develop discharge planning protocols with aged care and disability services.

Recommendation Seven
As a priority and in collaboration with the Department of Social Services (DSS), the National Disability Insurance Authority establish joint policy capacity dedicated to developing detailed cross sector interface arrangements; and that these arrangements facilitate the formation of integrated service pathways involving housing, health, aged care, disability services, transport and other relevant programs.

Recommendation Eight
That DSS undertake an audit of Younger People In Residential Aged Care (YPIRAC) funds in the States and Territories from 2011-2015 to locate where the funding has been used across the three YPIRAC target areas; and to identify the extent to which they are maintaining effort on YPIRAC objectives.

Recommendation Nine
That the Council of Australian Governments (COAG) direct the National Disability Strategy and the National Disability Insurance Scheme become standing items on meeting agendas of the relevant Ministers Councils.

1. Introduction

The Young People In Nursing Homes National Alliance welcomes the Senate's Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Like the Senate's 2004 *Inquiry into Aged Care* that included young people living in residential aged care as one of its five terms of reference, this Inquiry offers an opportunity to revisit the issue of Young People living In Nursing Homes (YPINH™). With the rollout of the NDIS underway, it's even more important that the YPINH issue is examined again in a contemporary context.

The Inquiry offers a significant opportunity to consider again why we have young disabled Australians being supported by an aged care system that is not designed to manage their needs; and an aged care funding regime that is completely unable to provide the necessary funding to support a younger person's social and emotional well being; deliver the staffing levels appropriate to their support requirements; or provide the customised equipment and rehabilitation input needed for a younger person to recover from catastrophic injury or exacerbation of disease episode.

Previous inquiries and service initiatives targeting YPINH have established who the YPINH cohort is, what influences their placement in Residential Aged Care (RAC) and how the issue may be approached. Rather than restate the problem, this submission concentrates instead on the systemic impact of these efforts to resolve the YPINH issue; looks at the beneficial outcomes achieved; and examines areas where evidence for reform has not been translated into policy and practice. It also canvasses the development of cross-sector service pathways as an evidence based approach to progress resolution of the issue.

Lastly, this Inquiry offers the chance, once and for all, to disabuse the notion that Young People living In Nursing Homes is an issue for disability services only. Instead, it is important to recognise that the solution to this longstanding problem lies with multiple program responses from health, housing, disability services and other mainstream programs; and development of the cross sector service pathways that YPINH need to have the 'lives worth living' in their communities they want.

The Alliance believes that this Inquiry has a key role to play in taking the YPINH issue beyond the conclusions reached by the Younger People In Residential Aged Care initiative; and to explode the myth that the problem will be fixed simply by the introduction of the NDIS. If it can do this, it will ensure that a focus on translation to action will be this Inquiry's signature result.

Further information about the composition of the YPINH group is included in this submission at Appendix A, while an outline of the factors influencing placement of young people in RAC is included in Appendix B.

2. The Young People In Nursing Homes National Alliance

The Alliance is a national peak organisation that promotes the rights of young disabled Australians with high and complex health and other support needs living in residential aged care facilities or at risk of placement there (YPINH); and supports these young people to have choice about where they live and how they are supported.

As Australia's first national peak representing younger people with disability and high and complex health and other support needs, the Alliance draws its membership from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state peak bodies, government representatives and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue by State and Commonwealth governments; develop policy initiatives at state and federal levels that promote the dignity, well being and independence of YPINH and their active participation in their communities; and ensure that young people living in nursing homes and their families have

- A voice about where they want to live and how they want to be supported
- The capacity to participate in efforts to achieve this, and
- 'A place of the table', so they can be actively involved in the service responses needed to have "lives worth living" in the community.

As the pre-eminent national voice on this issue, the National Alliance's primary objectives are to

- Raise awareness of the plight of YPINH
- Address the systemic reforms required to resolve the YPINH issue and address the urgent need for community based accommodation and support options for young people with high and complex needs
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver 'lives worth living' to young people with high and complex clinical and other support needs
- Provide on-going support to YPINH, their friends and family members.

Since its inception in 2002, the Alliance has argued for a lifetime care approach to development of supports and services for disabled Australians; and for collaborative arrangements between programs and portfolio areas including health, disability, aged care and housing to provide the integrated service pathways YPINH and others with disability require.

Over the last 13 years, the Alliance has developed a substantial body of work regarding the YPINH issue; and what is needed to resolve this longstanding problem.

2002 *Young People in Nursing Homes National Summit* and Report.

2003 *Unlocking Potential*: *National Conference on Young People In Nursing Homes*. Conference and Report

2003 Submission to the Hogan *Review of Aged Care*

2004 Submission to Senate Community Affairs References Committee *Inquiry into Aged Care*

2006 Submission to the Senate *Inquiry into the Funding and Operation of the CSTDA*

2006 Submission to the Senate *Inquiry into the Sale of Medibank Private*

2007 *National Summit on a Catastrophic Injury Insurance Scheme*. Summit and Report

2008 Submission to House of Representatives *Inquiry into Better Support for Carers*

2009 *Shaping the Future Today: 2nd National Conference on Young People in Nursing Homes.* Conference and Report

2009 Submission regarding the *Victorian Aids & Equipment Program Redevelopment Service Delivery Model Discussion Paper*

2010 Submission to the Department of Health and Ageing's *Review of the Aged Care Funding Instrument (ACFI)*

2010 Submission to the *National Carer Strategy consultation*

2010 Submission to Productivity Commission *Inquiry into Disability Care and Support*

2012 *YPIRAC2 the Next Steps*: *Report to the COAG Standing Committee on Communities, Housing and Disability Services*

2012 Submission to the Senate *Inquiry into the National Disability Insurance Scheme Bill*

2013 Submission to the *COAG consultation RIS on the NDIS*

2013 *Economic benefits of coordinated service delivery for YPINH* (with ACILTasman)

2013 Submission to the Senate *Inquiry into the Living Longer Living Better Aged Care Bills*

2013 Submission to the Senate *Inquiry into the Care and Management of Australians living with Dementia and behavioural and psychiatric symptoms of dementia*

2013 Submission to the Queensland Public Advocate's *Inquiry into people with disability in long stay healthcare facilities*

2014 *Cross Sector Service Coordination for people with high and complex needs: Harnessing existing evidence and Knowledge* (with Sydney University's Centre for Disability Research and Policy)

2014 *Shaping the Future Today*. *Transforming housing policy for Australians with disability.* Housing policy discussion paper with Monash University's MADA

2014 Submission to Treasury *National Consultation RIS on Motor Vehicle CTP schemes*

2014: Submission to the Financial Systems Inquiry

For more information about the Alliance and young people in nursing homes, go to www.ypinh.org.au

3. Timeline of activities and initiatives related to YPINH

The following table summarises the key activities and initiatives that address the YPINH issue and have been undertaken since the 1987 Disability Services Act. The list is not exhaustive as there are other State/Territory projects that have looked at resolving the YPINH issue. It does, however, demonstrate that YPINH have been and continue to be a priority issue. As the tables below shows, research, inquiries and practical service initiatives have all been completed, yet the problem remains.

The Alliance expects that this current Inquiry will examine this previous work and interrogate submissions and other evidence (particularly from State and Territory governments) to establish why some 20 years worth of evidence and experience has not been better translated into more effective system reform. The exception is the introduction of NDIS, which is a whole of system transformation. However, while the NDIS will enable a wider set of choices for people in the YPINH group, it is unlikely, on its own, to resolve what has become an entrenched problem.

TABLE 1 YPINH Activities & Initiatives Timeline

TIME	ACTIVITY	ACTIONS	OUTCOMES
1987-1990	National Attendant Care Scheme and Project 325 (as a part of the 1987 Disability Services Act programs)	Initiative to provide attendant care programs to young people with disability so they could move out of nursing homes and get support to live in the community.	The establishment of individual attendant care as a service model in Australia and a demonstration that young people with disability can live successfully in the community.
1993-1994	As part of a review of unmet need and growth factors for services funded through the Commonwealth State Disability Agreement (CSDA), the Disability Services Subcommittee of the Standing Committee of Community Services and Income Security Administrators endorses a NSW proposal to research and develop alternatives to the placement of younger people with disabilities in nursing homes for the aged.	Australian Institute of Health and Welfare (AIHW) undertakes a detailed review of 1995 estimates of unmet demand for disability accommodation, support and respite services. This is based primarily on data from the 1993 ABS Survey of Disability, Ageing and Carers and reviews questions that relate to the target group for CSDA services including the data on "younger people with a disability in nursing homes".	Review confirms inappropriate use of residential services does exist. Examples given included ▪ People using aged care nursing homes or hospitals as long-term accommodation, particularly following traumatic injury and because of the absence of suitable long-term accommodation support. ▪ People with Acquired Brain Injury being placed in group homes for people with intellectual disability "…where this may be inappropriate."

1995-1997	West Australian Government's YPINH Project	▪ Closure of Mount Henry Hospital (MHH). MHH was used as a residential facility to accommodate young people with disabilities in a "nursing home environment". Closure of MHH's 24 beds. ▪ Closure of 95 state nursing home beds providing long term accommodation to younger people with disability. ▪ Different accommodation models explored. ▪ Capital funding from the WA Health Department and Homeswest (WA Department of Housing). WA Health provides additional funding allocation for therapeutic equipment needs ▪ WA Health funding contribution of $6m PA to WA Disability Services Commission for 4 years. ▪	▪ Successful co-funding arrangements between state health, housing and disability services to deliver project. ▪ Delivery of targetted supported accommodation options. ▪ With the exception of the MS units and Brightwater Care Group's residential services, other supported accommodation offerings remained the province of disability services.
2003-2004	Commonwealth Innovative Pool Program's Disability Aged Care Interface Pilots Department of Health and Ageing	Provision of a pool of flexible care places outside annual Aged Care Approvals Rounds to trial new approaches for specific population groups including ▪ People with disabilities living in disability residential services who are ageing and at risk of placement in RAC ▪ Innovative pool funded individual top up packages that enabled allied health services to be delivered to residents that disability provider could not offer ▪ Defensive strategy from aged care to avoid preventable aged care admission ▪ Detailed AIHW evaluation ▪ 2 year timeframe, funding tied to individuals. Originally this initiative was designed to be a 12 week intervention model, but was extended to 2 years after negotiation with the Department of Health and Ageing.	▪ Successful co-funding arrangements between the Commonwealth Department of Health and Ageing and State Disability Services that was successful in preventing aged care entry ▪ Enabled 3 individuals with MS to move from RAC to community supported accommodation. Lack of program continuity deterred engagement by providers and senior state officials ▪ Noted clash between the prescriptiveness of the Aged Care Act and the policy and funding imperatives of state disability services.
2004-2005	Senate Inquiry into Aged Care	Had YPINH issue as one of Inquiry's five Terms of Reference. Recommendations included that all jurisdictions work cooperatively to: ▪ Assess the suitability of the location of each young person currently living in aged care facilities; ▪ Provide alternative accommodation for young people who are currently accommodated in aged care facilities;	Delivered a unanimous Committee report. Highlighted YPINH as a priority for both the disability and aged care sectors. Led to the Community Affairs Committee inquiry into the Commonwealth /State/Territory Disability

		▪ Ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options. ▪ 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.	Agreement (CSTDA). Inquiry report findings and recommendations influenced development of the YPIRAC initiative. Key recommendation for a mechanism to incorporate rehabilitation, health services and equipment was not adopted, (although equipment supply was included in the 5 years of YPIRAC, but ceased at 2011, except in Tasmania)
2006-2011	Younger People In Residential Aged Care initiative (YPIRAC)	▪ National partnership between federal and State and Territory Governments ▪ $244 million in 50/50 joint funding over 5 years ▪ 3 objectives: 1. Offer alternative support and accommodation options to younger people with disability living in residential aged care 2. Provide improved disability services into the nursing home for younger people with disability who were not able to move to the community or chose to remain in RAC 3. Prevent younger people with disability entering RAC	▪ Single program initiative involving only disability services at State/Territory and Commonwealth levels (50:50 funding). ▪ No involvement of the Department of Health and Ageing or aged care sector. No involvement of programs from Health Departments in any jurisdiction ▪ Mid Term Review of YPIRAC highlighted the need to secure access to rehabilitation services[1] ▪ YPIRAC delivered some benefits to some people over its 5 years (1,432 out of around 6,500)[2] but did not generate systemic benefit to health, aged care or disability programs ▪ Australian Government continued funding its 50% share beyond YPIRAC

[1] urbis, *Younger People in Residential Aged Care (YPIRAC) Program, Mid-Term Review Report*. Prepared for FaHCSIA by urbis, Sydney, 2009: 43.

[2] Of these, an estimated 250 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation); 244 people achieved the second YPIRAC objective (diversion from residential aged care); and 456 people achieved the third YPIRAC objective (receiving enhanced services within residential aged care) AIHW, *Policy Bulletin 103, Younger People in Residential Aged Care*, Canberra, April 2012.

			cessation in 2011: this not matched by States and Territories ▪ Trialled two highly successful coordinated care pilots for people with neurological disability in NSW and Victoria. This model, although highly effective in preventing aged care admission for younger people, was not continued in either jurisdiction.
2010-2011	Productivity Commission Inquiry into Disability Care and Support	Landmark inquiry investigating feasibility of a lifetime care and support scheme for Australia. System wide reform examined.	Identified the disability support system in Australia to be fragmented, underfunded and unfair. Detailed inquiry recommending a 3-tiered National Disability Insurance Scheme. Inappropriate accommodation of younger people with disability in aged care and healthcare facilities identified as a key rationale for the reform. Identified the importance of well developed interfaces between disability and other services areas. Supported an individualised funding model for participants and choice over services, including residential services.
2011	*YPIRAC[2]: the next steps.* Report to the Council of Australian Governments Standing Council on Community, Housing and Disability Services (SCCHDS)	Examined the design and implementation of the YPIRAC initiative. Outlined the implications of the design and operation of YPIRAC, identified residual service gaps , benefits delivered and identified key priorities for both levels of government to ensure the issue continued to be resolved over the subsequent five years. Highlighted the importance of engagement with sectors and service systems outside the disability sector.	Major recommendations included ▪ A cross sector service approach to development of integrated service pathways for YPINH with input from a range of different service programs ▪ A risk management approach to assess need and deliver service responses ▪ Direct involvement of

			state health departments and the federal Department of Health and Ageing in the initiative going forward. For a complete list of recommendations see pages 3-4 of the *YPIRAC*[2] Report.
2013	National Disability Insurance Scheme (NDIS)	Major reform initiative for the organisation and funding of personalized supports for people with disability in Australia. Staged implementation of insurance based lifetime support funding system. Implementation over 6 years. Commitment from jurisdictions to share NDIS funding costs with the Commonwealth and deliver in kind service commitments to the scheme.	Currently being implemented in the jurisdictions. Individualised funding and planning mechanism for disability services. Scheme objectives for social and economic participation of participants. Single program (disability) focus with intention to develop program interfaces with other mainstream programs. Reorganisation of service purchasing models and the service provider market.
2013	Queensland Public Advocate's *Inquiry into People with Disability in Long-Stay Health Care Facilities*	Investigated the issue of people with disability being long term residents in healthcare facilities in Queensland. Produced an influential report, *People with intellectual disability or cognitive impairment residing long term in health care facilities: Addressing the barriers to deinstitutionisation*.	Resulted in the identification of 280 people living in hospitals, residential institutions and other health care facilities at an estimated cost of $80m to the health system. Recommended a joint strategy to resolve the issue across the health, housing and disability portfolios. At the Premier's direction, the Queensland government subsequently implemented a 'Joint Action Plan' to work on locating alternative housing and support options for a group of individuals ahead of the NDIS roll out in Queensland.

2014	*Cross Sector Service Coordination for people with high and complex needs: Harnessing existing evidence and Knowledge*. YPINH Alliance and Sydney University Centre for Disability Research and Policy. Cross Sector Service Coordination research project and discussion paper.	An NDIA funded research project to analyse existing Australian and international evidence on cross sector service coordination for people with 'high and complex needs'.	Discussion paper found that evidence and experience supported cross sector services coordination as a key tool to ensure needs are met. Recommended vertical and horizontal integration of service programs, with key roles for governments, providers and people with disability and families. Recommended that cross sector service coordination be part of the NDIS design, not just a service type to be included in funding packages.
2014 - 2015	Community Affairs References Committee Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.	Contemporary inquiry into the system of residential services for people with disability, including aged care. Includes terms of reference for the role of the health and aged care systems in the development of pathways of support. Examining the activity within the States and Territories around the YPINH issue post YPIRAC including the NDIS.	Inquiry will inform the ongoing development of the NDIS and transition activity by all jurisdictions.

4. A longstanding problem

As the table above shows, there have been many different attempts over the last 25 years, to address the issue of young people living in aged care nursing homes. Each piece of work in the table has made a contribution to the broader change process we are seeing in disability services in Australia. As an issue, YPINH has been well understood by the community as a highly visible representation of the systems failure that the NDIS has ultimately been designed to fix.

Influenced by different policy and service imperatives, these varying attempts to provide a solution have advanced our understanding of why young people enter residential aged care (RAC) and what might be done to prevent this continuing. While still not widely acknowledged, two of the most obvious learnings from these different programs is that the YPINH issue is not just one for disability services programs alone; and the YPINH problem cannot be resolved simply by increasing the supply of traditional disability services.

Maintaining that the YPINH problem is the responsibility of disability services ignores the evidence that YPINH require concurrent access to multiple service areas. This means that an ongoing contribution from other programs including health, housing and sometimes even aged care is needed. Disability Services cannot be substituted for the specialist services offered in these programs (particularly health). However, their routine absence from the YPINH response to these young people means that disability services are forced to attempt such substitution.

Throughout the YPIRAC program, many residential services for YPINH were designed without the access to the health supports required by this group. This happened not because these young people didn't need such supports, but because disability services programs and selected providers had little experience in this area.

While the NDIS does offer an important component to the overall resolution of the YPINH issue, it is naïve to think that the Scheme itself is a silver bullet for the issue. It will certainly address the key issues around the timing and quantum of disability supports for a person at risk of aged care placement; and offer greater options for YPINH living in aged care (including options for moving out). But it must be part of an integrated suite of supports that includes health services, housing, transport and aged care.

Without such a multi program approach, aged care will remain the default option for many people in this cohort.

5. The Younger People In Residential Aged Care initiative (YPIRAC)

The 5 year YPIRAC initiative has been the only national response to the YPINH issue. With $244m in joint federal and state funding, the Council of Australian Government's (COAG) decision to proceed with the YPIRAC program was directly influenced by the some of the recommendations of the 2005 Senate Inquiry Report *Quality and Equity in Aged Care*; as well as a significant community campaign for

action on the YPINH issue.

Despite the evident goodwill behind COAG's announcement of the initiative at its February 2006 meeting, the YPIRAC program suffered from significant design flaws, chief amongst which was that YPIRAC was a single (disability) program response to be implemented by State and Territory Disability Services. The absence of the Department of Health and Ageing from the program's design and implementation meant that any systemic reform around the YPINH issue was unlikely. In addition, the absence of any co-design from YPINH stakeholders saw the program evolve into another bureaucratic disability services activity that eventually was absorbed back into the National Disability Agreement. The near exclusive focus on people under 50 also limited the program's effectiveness and opportunity.

Essentially, the YPIRAC initiative 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 by disability services programs in the jurisdictions; and had a primary focus on moving young people out of RAC. Its blunt targets failed to encourage systemic reforms and led to service responses that relied on 'stand alone' disability services, rather than the integrated outcomes the YPINH cohort requires, involving health, disability, housing and aged care.

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

In essence, the person-by-person approach used in YPIRAC was, while useful for those individuals who engaged with the initiative, unable to address the systemic causes of the YPINH problem. YPIRAC has, however, delivered small improvements in capacity in the existing disability service system, including development of some new support and accommodation services; and prevention of some young people entering RAC.

The clinical interventions the YPINH group required were not, however, integrated in the initiative, 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…,"[3] and identified this linkage as "…a key challenge for the YIPRAC Program".[4]

[3] urbis, Op Cit, 2009: 43.
[4] Ibid.

Despite these flaws, the YPIRAC initiative

- Assisted a small number of younger people to relocate to the community from nursing homes;
- Developed a small number of "group home" disability supported accommodation services;
- Provided vital aids and equipment to program participants;
- Delivered additional services to participants who chose to remain in aged care or were unable to transition to the community;
- Prevented a small number of young people from entering residential aged cares;
- Delivered two cross sector service coordination pilots (the Continuous Care Pilots in Victoria and New South Wales) that resulted in all pilot participants avoiding placement in RAC; and
- Reinforced the need for a multi program approach to resolve the issue once again.

From the Alliance's involvement in the various State and Territory YPIRAC implementation programs, the standout successes of YPIRAC were:

- The full funding of customised aids and equipment for people in aged care and for others in the YPINH cohort;
- Delivery of individual packages to people in the 'at risk' group to enable them to stay in their homes;
- The Continuous Care Pilots that successfully trialed a cross-sector service coordination model for people with neurodegenerative conditions.[5]

For a more complete analysis of the YPIRAC initiative, see the *YPIRAC[2]: the next steps* report the Alliance was asked to prepare for the Council of Australian Governments Standing Council on Community, Housing and Disability Services (SCCHDS). A copy of the *Next Steps* report has been provided to the Senate Community Affairs References Committee for its information with this submission.

6. Where did the YPIRAC initiative leave the YPINH issue?

Despite its shortcomings, the YPIRAC initiative delivered some key benefits and learnings. Ranging from reiteration of the need for integrated service pathways to the critical importance of aids and equipment to the health and wellbeing of these young people, the YPIRAC learnings are as relevant today as they were when the program was underway.

[5] See the full CCP reports from NSW and Victoria at www.ypinh.org.au/reports

The Alliance believes they have direct relevance to the rollout of the NDIS and the recommendations this Inquiry may consider, and include the following points:

The disability system cannot, on its own, support the complex health needs young people present with. A multi program response is needed.

Sam's story
After relocating from the country nursing home he had resided in without incident for 6 years, Sam transitioned to a dedicated disability supported accommodation service developed under the YPIRAC initiative for young people with Acquired Brain Injuries (ABI). Because of the disability provider's poor understanding of his health needs and a lack of adequate training for support staff, Sam developed pressure ulcers that required treatment in hospital. He also endured several bouts of aspiration pneumonia brought about by poor management of his PEG feeds. At his last hospitalisation, his father was informed that hospital staff would not administer antibiotics to treat his pneumonia, as they believed Sam no longer enjoyed a reasonable quality of life. After Sam's father threatened the hospital with legal action, Sam received the antibiotics he needed and recovered.

As a single program, disability services response, YPIRAC was unable to combine the delivery of the health services its participants needed and manage the complexity and intensity of their overall needs, whether in aged care or in the community.

Support and accommodation options developed through the initiative were largely congregate settings staffed by personal care workers not trained to manage the complex needs of their residents. Although YPIRAC residences received additional funding to manage the higher needs of residents, this additional funding did not prevent recurrent health crises occurring. The common response when a health crisis did take place was to call an ambulance and admit the individual to hospital via the emergency department. Pressure care issues and mismanagement of PEG feeds leading to aspiration pneumonias were all too common causes of recurrent hospital admissions for some young people living in these residences.

Then and now, the Alliance is aware of instances where disability service providers have refused to accept the return of the resident on discharge from hospital after several emergencies of this type, the resident's care needs deemed "too hard" to manage. The Alliance is also aware of several incidents in which medical staff, dealing with repeat incidents of aspiration pneumonias, have refused to treat the individual on the grounds that he or she lacks a decent quality of life and advised families to 'let nature take its course'.

Health outreach services; improved training of service providers and support staff in the different needs of the YPINH cohort; as well as the provision of nursing overlays in new supported accommodation services, were health interventions that could have provided the health supports YPINH moving out of nursing homes needed. YPIRAC's single program response meant that this was never considered.

Crucial need for health services

Because YPINH are largely those with disabilities acquired as the result of a health crisis delivered by a catastrophic injury or a progressive neurological disease, they present with complex health and functional disability needs that require a coordinated multi program response. Disability services can provide one part of that response only. Programs such as health, housing and aged care where needed, have a responsibility to deliver the specialist supports and services they provide and YPINH require.

Without the involvement of health programs, for example, the health outreach services YPINH require to safely manage their health needs in the community were not developed under YPIRAC. So too, the nursing overlays that could have made new supported accommodation services developed under the initiative's auspice safer for residents with complex health needs, were not included in the tender specs. Disability providers were left to assume their YPINH residents required the same disability responses as other clients without complex health needs; and support staff were not adequately trained to manage the intensity and complexity of need their clients presented with.

Despite the goodwill and best intentions of all involved, programmatic ignorance of the health support needs of YPINH meant that many who relocated to the community under YPIRAC were placed in an unintended situation of risk. The Alliance is aware of several YPINH who have physically deteriorated and in some cases, who have died as a result of inadequate management of their health needs by the YPIRAC disability supported accommodation service they moved to. Many more contacted the Alliance to ask that they be allowed to return to their nursing home where they felt their needs were better understood and more safely supported.

Co-funding arrangements, service collaborations and specialist program contributions must be brought together and coordinated across sectors to deliver the integrated care pathways YPINH need to maintain their health and well being.

To this point, the advent of the NDIS has, however, done nothing to trouble the view that improved availability of disability supports and services will solve the YPINH issue. Where the scheme confronts the extant health needs of a scheme participant, for example, it simply expects the health system to respond. Yet the health outreach services many YPINH require to live safely in the community do not yet exist.

Health services must be encouraged to develop these outreach services and do so not only because they have a responsibility to deliver the health supports all Australians require. In addition to the improved health and well being of the individual concerned, the availability of these services can ultimately lead to reduced use of hospital services and subsequent and significant savings to health budgets nationally, as well as improved health and well being for the individual concerned.

Ideally, these vital health outreach services (including delivery of rehabilitation in community settings) should be developed through collaboration between health services and the NDIS so that YPINH can get the full suite of supports they need, not just those defined by disability services programs.

Housing options

Mark's story

Mark was diagnosed with Multiple Sclerosis when he was in his late teens. Now a father of two young children, Mark lives with his wife and children in their family home that was adapted several years ago to accommodate his mobility needs.

As Mark's disease has progressed, he has needed higher levels of support and allied health input to maintain his capacities and to support him during his disease progression. The unwillingness of the disability system to increase Mark's funded support as his needs have changed and as care agencies have increased their fees each year, has meant that he is at ever escalating risk of placement in a nursing home or a residential disability service.

Because these residential services cannot accommodate family units, Mark would be forced out of his family should he have to enter residential care. This is something he wants to avoid at all costs. Although his family is his priority, Mark is also concerned about his ability to maintain his community networks if he is forced into a residential setting.

The desire of scheme participants to live independently in the community is also causing the NDIS to look to provision of housing. The prevailing view, particularly amongst disability service providers who have been contracted to both build group homes and provide the support services to residents living there, is that they should continue to be the agencies responsible for developing new housing stock. Yet building more group homes will not satisfy the expectations that YPINH and other individuals with disability have to live independently and as valued members of their community.

Having had an able bodied life before acquiring their disability, many YPINH do not identify as disabled and do not wish to live with others with disability. Most simply want to return to live in the community they have previously resided in, with the suite of supports they need.

However, the disability system's evolution in response to the needs of individuals means that group homes are no answer for YPINH, particularly those who are parents of young children. Many individuals had to face the dilemma of losing their family if they moved into one of YPIRAC's group homes. Many chose not to move because of what they would have to give up.

Alternatively, if they chose to remain at home with inadequate resources to manage their 24-hour care needs, they faced living in a state of continued stress in regard to the support provided by their family carers.

The involvement of housing programs and the latter's investigation of alternatives to group homes as accommodation options, may have resulted in innovative responses that catered to the needs of this YPINH subgroup if housing services had been included in YPIRAC's implementation.

As it was, housing programs' lack of involvement in YPIRAC meant that disability services simply reverted to business as usual and built more group homes.

To redress this imbalance, state housing programs must look to partner with builders, developers and the communities in which they wish to develop housing options, if the innovative responses YPINH and others with disability are looking for are to be delivered.

The Alliance has recently completed a housing policy discussion paper that supports community consultation and development as integral to housing developments for Australians of all abilities; and looks to innovative practice in Australia and internationally that has delivered this successfully. A copy has been provided with this submission for Committee members' information. See also http://www.ypinh.org.au/ypinh-alliance-launches-housing-policy-paper

The governance of the YPIRAC initiative

The YPIRAC initiative was governed by bi-lateral agreements that had clear targets, timelines and funding arrangements. While a number of jurisdictions struggled to meet their targets during the program's implementation for a variety of reasons, these jurisdicitons were clear and relatively transparent about the difficult task they had to meet the targets.

When YPIRAC finished in 2011, the Australian Government committed to continue funding its $122m contribution to the initiative beyond YPIRAC's close to ensure continuity of the services that were established. Following its end in 2011, the initiative was rolled into the National Disability Agreement (NDA) and YPINH was made a priority area of activity for the jurisdictions.

Since then, with the YPIRAC targets gone, it has been difficult to track how the States and Territories have maintained this priority. In many jurisdictions we have seen it become increasingly difficult to secure top up funding for YPINH (including for equipment), particularly at discharge from acute care.

Indeed, since the NDIS has begun, the gap between what is available inside and outside the trial sites has widened dramatically. While some States indicated that they would quarantine YPIRAC funding packages and residential places for future YPINH, our experience since 2011 is that this commitment has not been observed.

In NSW, for example, we have seen evidence of people with YPIRAC packages in the Hunter region go into the NDIS and the NSW government count the YPIRAC package

as part of that state's in-kind contribution to the scheme – despite the package being 50% funded by the Australian Government. It is difficult to establish whether the NSW government backfilled this package for another YPINH outside the Hunter. But this is a question we would like the Inquiry to put to the NSW Government.

Another disturbing example, is advice we have received about the Disability Services Commission (DSC) in Western Australia removing the YPIRAC funding from a diagnosis specific YPIRAC residential service that began with 3 YPIRAC funded residents and 3 funded directly by the DSC.

With the recent death of one of the original YPIRAC funded residents, the DSC has indicated that, from this point, their intention is to take back any YPIRAC packages and put them into DSC's general disability funding round. If this happens, the service's capacity to provide the specialised support it is designed to deliver may be compromised. The risk then, is that this and other future vacancies may be filled with people with other disability types, simply because it suits the waiting list system. The fact that some people in this diagnostic group are reluctant to identify as 'disabled' and do not register for vacancies, reinforces the fact that this type of funding round allocation system is not suitable for this group.

This type of move by the DSC could result in reduction of specialised accommodation services, such as this one, that are extremely rare and greatly needed. Yet without the dedicated YPIRAC funding it relies on, the service faces the very real risk of becoming unviable if that funding is not left with the service.

A one size fits all approach to funding allocation for residential services may suit the bureaucratic imperative, but is ineffective and counterproductive for individuals and providers.

We appreciate that there is great pressure on the State and Territory Disability systems. But given that there is still a need to target YPINH issues post YPIRAC, we wonder about the strategy behind generalising the YPIRAC funding, other than to meet broad demand for funded support. Getting the jurisdictions to explain this strategy to the Inquiry would be instructive.

The National Disability Agreement's (NDA) accountability mechanisms are such that the States and Territories could flush the YPIRAC money through their general system and not be answerable. Without the data to track the YPIRAC packages it has become impossible to find this money, or to measure how the State and Territories are meeting their NDA priority obligations in regard to YPINH.

While the NDA is in transition to the NDIS, the Alliance has major concerns about the transparency and accountability of the jurisdictions in this process.

Aids and Equipment

Access to necessary aids, equipment and home modifications was one of the more successful features of YPIRAC. Because people living in residential aged care were ineligible for State and Territory equipment schemes, YPIRAC was the only way younger people in aged care could get the customised equipment they needed. The program also gave more rapid access to equipment for those in the 'at risk' group.

Lack of access to essential equipment has long been a devastating problem for YPINH. This has been the result of an arbitrary bureaucratic exclusion of YPINH based on the presumption that because people reside in a Commonwealth program rather than a State program, the Commonwealth (aged care) program is responsible for their equipment needs.

This is a direct cost shift from the States to the Commonwealth and in no way addresses the needs of YPINH. Our experience suggests this is false economy. It doesn't save the States and Territories money in the long term, as the downstream problems arising from poor equipment provision end up in the hospital systems in those jurisdictions. This also shifts the risk of poor health and quality of life to YPINH and delivers significant standards compliance risks to aged care providers.

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[6] ($85,000 in 2013 dollars), with 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 pressure equipment in aged care and disability settings.

Different jurisdictions dealt with equipment purchase in different ways, but the fact that this service was available was a positive and necessary inclusion in the YPIRAC initiative.

> One important risk factor is the rapidity with which equipment needs can change. Some clients required up to three revisions of wheelchair and 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.[7]

The fact that the experience and evidence from YPIRAC did not initiate national reform of equipment schemes to include people living in aged care, was a major disappointment. NSW and Victoria both went through extensive redevelopment of

[6] Australian Wound Management Association, *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*, Cambridge Publishing, West Leederville, WA, 2001.
[7] See MS Australia and Calvary Healthcare Bethlehem, *The Victorian Continuous Care Pilot – Final Report*, Melbourne, 2009: 64.

their aids and equipment schemes during YPIRAC, but without expanding eligibility to YPINH. Queensland, South Australia and Western Australia still exclude people with disabilities who are residents in aged care facilities. While in some jurisdictions equipment is purchased as part of individual packages, many YPINH are not accessing these packages and, as a result, are excluded on this front as well.

Only Tasmania expanded eligibility of its equipment scheme to people under 65 in aged care in the years that YPIRAC was operating.

Since YPIRAC finished in 2011, the Alliance has been approached by a number of YPINH in NSW who had their equipment fully funded through the YPIRAC initiative. These young people need their equipment repaired or replaced, but have been told by the NSW Enable equipment program that they are ineligible because they are living in residential aged care. Despite YPIRAC funding providing the initial equipment, Enable's equipment program takes no responsibility for current needs because 'the YPIRAC money has gone' and these young people are seen as the "responsibility" of federal aged care.

There is no stronger example of the failure of YPIRAC to deliver sustainable reform than this type of program behaviour. YPINH in other states are experiencing similar responses from their equipment programs.

In Victoria we have noted departmental resistance to even approving the purchasing of equipment from individual YPIRAC support packages for people in aged care. One young person in rural Victoria wanted to use some of her YPIRAC package to buy her own portable hoist to enable her to leave the nursing home and access the local community. She was denied approval to use part of her YPIRAC package because 'it is the nursing home's responsibility to provide equipment for its residents'.

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 fund the necessary customised equipment (such as electric wheelchairs, customised seating, high end pressure mattresses, communication aids or a tilt in space commode chair).

Despite the *Living Longer Living Better* aged care reforms, aged care funding levels remain inadequate to support of the needs of younger residents with disability. Indeed, the *Living Longer Living Better* reform's declaration that aged care service providers must provide for all their residents needs, regardless of cost, has resulted in aged care providers increasingly refusing to take a younger person because of the higher costs associated with their care, costs that providers are now required to meet from limited aged care funding schedules.[8]

[8] Outlined in the Specified Care and Services Schedule, are those items RAC providers are required to provide, despite cost. There are numerous areas within the schedule that are applicable to younger people, such as customised equipment and community connectedness where the latter can involve

If nursing homes are to provide a viable long term or transition option for younger people with disabilities, the hotel service aged care can offer must be augmented by co-funding and other service contributions from disability and health services particularly and other programs as needed.

This reform is a logical step and the Alliance sees this as an important part of transition to the NDIS, as the scheme will cover these equipment needs for participants in aged care. Because of the ever present risks to residents, this reform needs to be fast tracked and not left to follow the NDIS rollout timeframe, as it leaves too many people without an essential service.

Rehabilitation

Access to rehabilitation is another longstanding service gap that contributes to the complexity of the YPINH issue and the inadequacy of current residential services for this group.

There is an underlying assumption in many cases that the aged care service or disability residential service can cover in some way for the rehabilitation needs of people in the YPINH group. While this is clearly not the case, the fact is that there is a lack of rehabilitation capacity in all jurisdictions to make this so, with the result that disability and aged care leaders have consistently been unable to generate any pressure on their health counterparts to expand provision of these vital services.

As indicated earlier, the YPIRAC *Mid Term Review* recommended that work be done to improve access to rehabilitation as part of the YPINH response, yet little has been done to make this a reality.[9]

Standard rehabilitation models in Australia do not utilise the kind of long-term slow stream 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 existing rehabilitation programs. Denial of rehabilitation input can lead to preventable adverse health outcomes. It can also be a direct cause of inappropriate aged care admission or the preventable deterioration of function for people living in aged care.

Prior to YPIRAC in Victoria, for example, the lack of rehabilitation or accommodation options was a major problem facing hospital discharge teams.[10] The Alliance sees this as a critical problem still, particularly where people have significant unmet

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the costs of leaving the nursing home to access the community, cost that can be much greater than those incurred in supporting an older person. See the *Quality of Care Principles 2014* at http://www.comlaw.gov.au/Details/F2015C00075/Html/Text#_Toc409692213

[9] urbis, Op.Cit: 43.

[10] Strategic Projects Branch, Victorian Department of Human Services, *Creating New Opportunities; Responding to the needs of younger people in Victoria's residential aged care services*, Melbourne, 2005: 42.

rehabilitation needs. The current aged care assessment model does not capture the ongoing rehabilitation needs of YPINH and the ACFI fees in no way allow for meaningful rehabilitation responses to progress. While YPIRAC was able to provide equipment and some lifestyle based service enhancement services, it did not provide rehabilitation.

Targeted programs do, however, exist that are useful models in this context. The Victorian *Slow to Recover Acquired Brain Injury Program (STR)* and individual rehabilitation packages in Western Australia, are two examples that demonstrate that the expanded specialist inpatient and flexible community based rehabilitation services the YPINH group needs, can be effectively delivered.

In addition to better recovery and independence benefits to individuals, rehabilitation has potential systemic cost benefits. 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.*[11]

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 anywhere from $158,522 for someone with high and complex needs, to $78,390 for someone with low support needs.[12]

The Alliance believes that joined up reform needs to occur across the health, aged care and disability programs so that skilled rehabilitation services become an integral part of YPINH care pathways.

The tension in this reform is that the health system is primarily geared for episodic interventions, whereas slow stream rehabilitation is a long-term commitment. Essentially, though, the health outcomes of YPINH should be the responsibility of the health system as much as the disability support system. For this reason, governments need to deliberately incentivise and encourage the joining up of these systems.

[11] ACIL Tasman, *Oates Street facility redevelopment: a cost benefit analysis*, Perth, 2010: vii.
[12] urbis, Op.Cit: 16.

Cross sector coordination and integrated care pathways for YPINH

The need for cross sector service coordination and the development of integrated care pathways for the YPINH cohort is not a new observation. This point has been made numerous times and recommended by many of the activities outlined in the *YPINH Activities & Initiatives Timeline* table on pages 5-12 of this document, including

- Senate Community Affairs References Committee 2005 Inquiry Report, *Quality and Equity in Aged Care*
- 2007/8 YPIRAC Continuous Care Pilots
- 2010 *YPIRAC Mid Term Review*
- 2012 *YPIRAC [2] The Next Steps Report*
- 2014 YPINH Alliance & Sydney University's *Cross Sector Service Coordination Discussion Paper.*

But despite enthusiasm for whole of government responses to these kinds of entrenched problems, there has been a persistent reluctance from the jurisdictions to engage in this cross sector work.

This was brought into sharp relief by the limitations of YPIRAC's single program response. YPINH involved in the YPIRAC initiative needed program responses from health, disability, housing and aged care.

Because disability services was the only program participating in the initiative, the integrated responses YPINH require were not delivered.

Now 4 years post YPIRAC, nothing has changed in this regard, and state disability services remain the "go to" program for response, both on discharge from acute care and when informal care for complex health needs fails in the community.

Unless the NDIS forges the necessary cross sector coordination options with health and other programs that YPIRAC was unable to do, the systemic response to people in the YPINH cohort will continue to be deficient. No amount of planning or additional choice and control over their disability services will address the ongoing health needs of people needing a comprehensive support regime. To address this fully needs a systemic response, not the series of individual responses YPIRAC delivered.

Whether this avoidance of joined-up initiatives has been related to the conception by mainstream programs that YPINH is simply a disability services issue; or whether disability services programs themselves continue to fundamentally misunderstand the issue, failing to take the evidence of cross sector service pathways' value for YPINH seriously, is not clear.

Whatever the case, there is clear evidence that this lack of systemic engagement is a key factor in both the perpetuation of the YPINH problem and the enduring lack of structural solutions needed to resolve it.

In summarising the imperative to get disability and aged care programs to work together to reconcile key questions about their program design and translate the success of the pilot into practice, the Commonwealth Innovative Pool's Evaluation Report observed:

> *The Pilot has achieved successful outcomes for individuals and participating services. It has also highlighted that questions remain concerning the separate identification of aged care needs in people with a disability and the respective roles of aged care and disability services. In this sense the Pilot has also helped to sharpen the focus on these two key issues. The AIHW evaluation team does not purport to have answers to these questions but considers them to be worthy of further consideration and debate….*[13]

The reality is, however, that this work has not been done and the incompatibilities and grey areas between aged care and disability services remain to this day. Because of its design as a disability services-only response, YPIRAC did not even consider these questions over its 5 year existence.

These questions remain live and unresolved and need to be tackled in the lead up to the NDIS. A key question for this Inquiry is: where is the overdue policy leadership for cross government reform in this area going to be located?

If, in the 9 years since the Innovative Pool Evaluation Report was delivered, aged care has turned its back on these issues and disability services programs (despite the offer of additional commonwealth funding if they could make this model work) have also ignored this opportunity, how are these still relevant questions best resolved?

Highlighting the need to achieve better cross sector development here is not meant to diminish the key roles of funding and service development. All are important.

But even where the NDIS can resolve the funding shortfall that has beset state disability services for decades, YPINH will still need housing, healthcare (including rehabilitation) and other service supports, as well as a mechanism that can bring them all together.

While there have certainly been systemic blockages in translating much of the evidence and learnings from previous YPINH focused work (particularly about cross sector approaches), there are some standout exceptions.

[13] AIHW, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot, Final Report*, Canberra 2006: 20.

In Queensland, the State Government has pursued the recommendation of the Public Advocate's Inquiry into longstay patients in healthcare facilities to establish a joint taskforce to address the issue.[14] The Queensland Government's Joint Action Plan team comprises senior representatives from the Health, Housing and Communities (disability services) departments to work on a strategy to find alternative housing and support options for the identified individuals.

Despite only limited funding to pursue this work, the initiative has been mandated by the Queensland Premier and is an important part of Queensland's readiness for the NDIS.

This approach followed another highly effective cross sector program in Queensland, the Queensland Spinal Cord Injury Response (SCIR). Developed in response to the fragmented state of key programs required by Queenslanders with spinal cord injury to return home to live in the community, the SCIR initiative involves the same departments of Health, Housing and Communities (disability services) working to bring their programs into alignment around individuals and their families.[15]

The Cross Sector Service Coordination Discussion Paper that has been provided to the Senate Community Affairs References Committee as an addendum to this submission presents an organising framework for this topic, outlining where both vertical and horizontal integration across sectors is required. This means that governments, service organisations, consumers and families all need to be involved to achieve good service integration. Simply leaving it to governments to make bi-lateral agreements as response, allows jurisdictions and programs to get stuck on 'who pays for what' rather than 'who does what, how and in partnership with whom'.

If we are to make progress on the YPINH issue, it is imperative that we move beyond the one-dimensional approaches that have marked the systemic response to this issue till now.

Aged care will remain one of the options on the spectrum for YPINH

> Dale lives in a nursing home in a rural town near the NSW/Victorian border. With the nearest supported accommodation option 200kms away, he has chosen to live in the nursing home to stay near his elderly parents who live nearby. Dale uses the nursing home's "hotel service" to provide his accommodation, personal support and some meals. Dale owns an art gallery that showcases the work of local artists and leaves the nursing home every day to open and manage the art gallery.

[14] Queensland Public Advocate, *People with intellectual disability or cognitive impairment residing long term in health care facilities: Addressing the barriers to deinstitutionisation*, Brisbane, 2013.
[15] See Griffith University, *Review of the Spinal Cord Injuries Response*, Disability Services Queensland, Brisbane, 2008.

Of the estimated 1432 younger people with disability who were assisted by the YPIRAC program over its 5 years of operation, approximately 250 young people (or 17.5%), moved out of residential aged care to supported disability accommodation.[16] This is but a fraction of the some 6,500 YPINH who were eligible for the program's assistance.[17]

As these figures indicate, large numbers of YPINH who were eligible for the YPIRAC initiative's assistance to move out of their nursing home, chose instead to remain living there and did so for a range of reasons.

For some in rural and remote areas, remaining in the nursing home was the only way to stay close to family, friends and community. For others, disability services' failure to provide the supports they needed had forced their entry to RAC. These individuals did not trust disability services to "get it right" this time and took a 'better the devil you know' approach to offers of relocation to the community.

A significant number of younger people, many with progressive neurological diseases, were simply unable to relocate to the community because the health services they needed to sustain them there did not exist.

In choosing to remain in residential aged care, these YPINH evidenced the fact that nursing homes will remain one of the 'options on the spectrum' for some YPINH for some time to come.

However, the clear reality demonstrated by the YPIRAC program is that even with dedicated funding, a bi-lateral intergovernmental agreement, a target group and established service purchasing arrangements, moving people out of aged care is not straightforward.

This can be seen in the opening of the most recent YPIRAC funded house in NSW in January 2015[18], more than 8 years after the commencement of the YPIRAC initiative. While most jurisdictions met their targets to create new accommodation options, service developments that involved new capital projects took many years after the start of the program in 2006 to complete.

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[16] 244 service users (17.0%) achieved objective 2 — people at risk, diverted from inappropriate admission to residential aged care. 456 service users (31.8%) achieved objective 3 — people provided with enhanced services within a residential aged care setting, for whom residential aged care is the only available, suitable supported accommodation option. SCRGSP (Steering Committee for the Review of Government Service Provision) 2013, *Report on Government Services 2013*, Productivity Commission, Canberra: 14.50-14.51.

[17] YPIRAC's limited funding and its focus on its "initial target group" of those under 50 years, meant that those over 50 years had little opportunity to participate in the initiative before available funding was exhausted. As a result, participants in the program were drawn largely from the under 50s group.

[18] See https://www.northcott.com.au/news/aged-care-no-place-ben

The expanded funding stream the NDIS will deliver means that alternatives and options for better support will certainly increase. But this alone will not completely forbid aged care as an option for some younger people with complex needs, whether they choose to live in a nursing home or not.

It has been suggested that aged care could be seen as a transition option in the short to medium term for individuals who cannot (or who do not want to) stay in hospital, and for whom there are no immediately suitable housing options.

The reality is that until we have a human services system that can deliver health outreach services to address complex health problems in community settings; until we have capacity to offer a range of housing options that suit individuals, parents of young families and other groups; until we have a workforce trained in the management of complex health and functional disability support needs in community settings, aged care *will* remain one of the options on the spectrum for young people with complex health and functional disability support requirements.

In this context, aged-care-as-transition must have clear entry and exit expectations around development of community based options; as well as delivery of multiple program offerings from health, disability and other programs, into the nursing home. If nursing homes can provide a 'hotel service' to a younger person, a service that is augmented by health in reach services, disability funding to deliver improved staffing capacities for younger people and community access opportunities, aged care can provide a viable transition option for younger people with complex health and disability support needs until the community options needed are available or developed.

In 2001, a Victorian Government policy paper on YPINH gestured to just such an option when it reported that

> *…a key finding of the Project is that, with additional funding to improve the service response or as a transitional option, RAC services can provide an effective model of care for some younger people with severe disabilities and very high clinical care needs.*[19]

Operating in Victoria at this time was the *Acquired Brain Injury Slow To Recover* rehabilitation program (STR) that provided flexible rehabilitation input to young people living in aged care.

In addition to its rehabilitation services, STR case management input would seek out alternative housing and support options for STR participants. For some of these STR program participants, aged care was indeed transitional.

While funding and other constraints meant that not all eligible individuals were able to access STR as they needed, the STR program offers a best practice example of

[19] Strategic Programs Branch, Victorian Department of Human Services, Op. Cit: 5.

younger people using aged care as a hotel service that delivers 24 hour support, to provide a stepping stone to life in the community.

In their 2013 economic analysis of coordinated care for YPINH, ACILTasman also described the option of aged care as a transitional service as a way of meeting "…a need for 'transition' – time, resources, accommodation – between exit from acute care and eventual return to community life."[20] ACILTasman declared that

> *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.*[21]

While its provision of home modifications will enable the NDIS to assist some people to return to their homes, other housing pathways and options obviously need to be developed. Using aged care as a transitional option to provide a hotel service augmented by other programs' funding and service offerings, can provide the breathing space needed for the development of housing and service options in the community.

However, a precondition for aged care to provide such a transition option would be that inter-program agreements are developed to ensure that co-funding supports for YPINH from health, aged care and disability services are routinely available and well coordinated.

Until the NDIS is fully rolled out and mature, these cross sector agreements will be crucial to successfully addressing the YPINH issue.

YPIRAC's dedicated focus on those under 50 years of age resulted in many YPINH over 50 who were eligible for YPIRAC under the terms of the COAG agreement, become ineligible under the jurisdictions' terms of implementation. The very strict rules that emerged around this age cut-off created significant difficulties for the integrity of the program, particularly in the aged care sector.

This factor was a notable representation of the highly bureaucratic approach taken to what was intended to be a first step in a longer process to address the YPINH issue. In this sense, YPIRAC's rigid and bureaucratic approach stands as an instructive counterpoint to the NDIS' stated strategy to learn and evolve from the activity in the trial sites on its way to full scheme rollout. However, the NDIS needs to remain vigilant to avoid falling into the same trap.

[20] ACILTasman: Op. Cit: 5.
[21] ACILTasman: Op. Cit: 16.

Issues related to aged care's capacity to mange the needs of younger residents

Residential aged care has long been seen as inappropriate for younger people. There are many dimensions to the issue including those that relate to the structure, purpose and operation of the sector, rather than the behaviour of individual aged care providers.

Even though the YPINH issue is not new, it is not a headline issue for aged care. While industry peak bodies are concerned about the capacity of the aged care system to support younger people, the legislative and commercial frameworks of the sector itself provide little guidance. The result of some hard learnings by providers, it is now commonly accepted across the industry and beyond that aged care funding is totally inadequate for younger residents.

Aged care services have been developed to respond to the needs of frail older Australians in the end stages of life. Aged Care funding alone cannot provide the

- Customised equipment younger people commonly require;
- Community access to enable them to leave the nursing home and maintain contact with social networks, family and friends;
- Rehabilitation services to recover from a catastrophic injury or an episode of disease exacerbation;
- Higher staffing levels needed to manage the intensity and complexity of need YPINH present with.

Despite the *Living Longer Living Better* aged care reforms, aged care funding levels remain inadequate to support of the needs of younger residents with disability because aged care's funding structure is not designed for this group of residents. Yet aged care providers are forced to make the funding level fit as best they can with their younger residents.

The *Living Longer Living Better* reforms' declaration that aged care service providers must provide for all their residents needs, regardless of cost, has resulted in aged care providers increasingly refusing to take a younger person because of the higher costs associated with their care, costs that providers are now required to meet from limited aged care funding schedules.

Unless there are external resources from another funding program around particular individuals, such as the *Slow To Recover* program; or collaboration through secondary consultancy from a diagnostic disability provider (such as an MS Society) is provided, aged care staff remain untrained in the different needs of younger people. While training and in-servicing are critical elements in ensuring that the aged care workforce can deliver appropriate services to younger residents, rosters, routines and service culture in aged care can also be barriers in this regard.

The Alliance has seen notable exceptions to this norm, where aged care providers work to ensure a positive and capable approach to supporting a younger resident by involving external specialist resources and ensuring that the resident and their family are central to the design and delivery of supports.

Given the proven inadequacy of aged care funding levels for younger residents, a key question for this Inquiry is whether, prior to the full rollout of the NDIS, the aged care funding structure should be

a. Retrofitted with an additional boosted funding level for residents under 65 years, or
b. Disability services programs should be required to co-fund the supports for these residents in aged care.

Workforce issues are commonly raised with the Alliance as problematic where younger residents are concerned. Residential aged care does not have mandated staffing levels and are staffed at much lower levels than disability supported accommodation services.

Younger people are often bigger and heavier than frail older people and can require 2 members of staff for transfers and personal care. Lower staffing levels mean staff are often unable to respond in a timely manner to the needs of a younger person. As example, if 2 staff are not available to assist a younger person to the toilet, the individual may be offered a pad to use in bed. The consequent loss of continence skills means transitioning to the community is much harder and young people need to reacquire these skills if they are to successfully return to life in the community.

The Alliance is aware of instances where the longer time needed to assist a younger person consume their meal and a lack of staff available to assist, has resulted in the nursing home requesting a PEG tube be inserted into the individual's stomach to supply nutrition because staff simply did not have the time to assist with meals. Using a PEG meant that once the liquid flow was adjusted the staff member could leave to attend to other residents.

While aged care industry peaks have indicated to the Alliance that a lot of goodwill and capacity exists in the aged care sector, the ACFI funding limits, the new legislative framework requiring providers to meet all resident needs and the inability to secure co-funding with disability, equipment and health services at the State/Territory level, are significant disincentives to accept younger residents.

With the introduction of the *Living Longer Living Better* framework, there are a number of incompatibilities with the disability sector that need to be worked through, including the issue of co-payments and standards. Given that 4-5% of aged care places have been occupied by people under 65 for decades (and will likely continue at these levels for some years to come), it is important that the aged care

system formally recognises their presence in the system's legislation, funding, policy and standards arrangements.

We expect that these issues will be live topics relevant to the NDIS rollout in the transition phase up to 2019. A process needs to be established so the aged care system can work through the interface issues with the disability services programs, the NDIS and the health systems in the interim.

References

ACIL Tasman (2013). *Economic benefits of coordinated service delivery for YPINH*, Report prepared for Young People In Nursing Homes National Alliance, Melbourne, 2013. Unpublished.

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

AIHW, *Policy Bulletin 103, Younger People in Residential Aged Care*, Canberra, April 2012.

Australian Government, *Report of the Senate Inquiry into Quality and Equity in Aged Care*, Commonwealth of Australia, Canberra, 2005.

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

Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report,* Melbourne, December 2009.

ComLaw, *Legislative Instrument Compilation, Quality of Care Principles 2014,* Canberra, January 2015. Available at http://www.comlaw.gov.au/Details/F2015C00075/Html/Text#_Toc409692213 Accessed 6 February, 2015.

Goldblatt, B., Muir, K., Meltzer, A. and Dinning, B. *NSW Continuous Care Pilot Evaluation*, Disability Studies and Research Centre, UNSW, Sydney, 2010.

Griffith University, *Review of the Spinal Cord Injuries Response*, Disability Services Queensland, Brisbane, 2008.

Hales, C., Ross, L. and Ryan, C., *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, AIHW, Canberra, 2006.

Jones, G. and Lawn, R. *The Young People In Nursing Homes Project Evaluation, Reports One, Two and Three*. Prepared for the WA Disability Services Commission, Perth, 1999.

Office of the Public Advocate, *People with intellectual disability or cognitive impairment residing long term in health care facilities: Addressing the barriers to deinstitutionisation*, Brisbane, 2013.

Productivity Commission, *Disability Care and Support, Inquiry Report*, Vols. 1 and 2, Report No 54, Canberra, 2011.

Strategic Projects Branch, Victorian Department of Human Services, *Creating New Opportunities: Responding to the needs of younger people in Victoria's residential aged care services*, Melbourne, 2005.

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

Victorian Department of Human Services, *Acquired Brain Injury Slow to Recover Program review. Final Report*, HDG Consulting Group, Melbourne, 2004.

Young People In Nursing Homes National Alliance and Centre for Disability Research and Policy, University of Sydney (CDRP), *Cross Sector Service Coordination for people with high and complex needs: harnessing existing evidence and knowledge*, Melbourne and Sydney, 2014.

Young People In Nursing Homes National Alliance and Monash University's Art Design and Architecture Studio, *Shaping the Future Today. Transforming Housing Policy for Australians with Disability*, Melbourne, 2014.

Young People In Nursing Homes National Alliance, *YPIRAC^2: the next steps. Report to the Council of Australian Governments Standing Council on Community, Housing and Disability Services (SCCHDS)*, Canberra, 2011.

Appendix A

Who are Young People In Nursing Homes (YPINH)?

The YPINH cohort includes individuals with a variety of acquired disabilities and high and complex health and other support needs who are under 65 years of age. These younger people can be categorised into 2 main groups:

- YPINH living in residential aged care facilities
- YPINH living in the community who are at risk of placement in residential aged care.

The main groups within the broader group of young people in nursing homes are people who

- Have sustained catastrophic injuries in motor vehicle or other accidents (including assaults or domestic accidents) where compensation is not available. They are in nursing homes because of the poor capacity of fault-based insurance schemes to provide for rehabilitation and lifetime care and support.
- Have sustained complex disabilities through hypoxic acquired brain injury (ABI). This can be caused by a number of unpredictable health events such as asthma attacks, drug overdoses, cardiac arrest, stroke or burst aneurism, episodes of meningitis or encephalitis, or near drownings.
- Live with disability arising from progressive neurological diseases like Multiple Sclerosis, Muscular Dystrophy or Parkinson's Disease, as well as those with Young Onset Dementia (YOD). A common trajectory for these YPINH is that debilitating disease progression combined with inadequate funded supports at home results in hospitalisation, then placement in aged care because returning home safely is no longer an option.
- Are living in the community with deteriorating or volatile health and fragile care arrangements. This includes people with a range of congenital disability, living in residential disability services that struggle with capacity to support them. Because these individuals are at real risk of premature placement in residential aged care, there is a clear imperative for measures that can prevent this placement outcome.

The YPINH cohort thus has the following characteristics.

- Disabilities encompass those acquired from catastrophic injuries including acquired brain injury (greater than 50 per cent of the cohort) as well as progressive neurological diseases such as Multiple Sclerosis, Parkinson's and Huntington's Diseases.
- High and complex support needs profile.
- High and complex clinical support needs profile.
- Need for ongoing 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.
- Critical dependence on Aids and Equipment to maintain health and well being including requirements for high end pressure care and equipment.
- Unwillingness to identify as disabled due to having an able-bodied life previously. YPINH consequently hold different expectations of, and aspirations for, the service system that include
    - Access to supports 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 a nuclear family.

The majority of younger residents in residential aged care are categorised as high dependency residents.

Long stay health care patients

As well as those in or at risk of placement in RAC, there are a growing number of young people unable to be discharged from hospital settings. They remain in hospitals or other healthcare settings either because community options do not exist; or the chronically under-resourced human (disability) services system lacks the funding to safely progress discharge to a community setting, even if a vacancy is available.

The Alliance is aware that RAC facilities are increasingly refusing to accept these young people on discharge from hospital. One of the outcomes of the Younger People In Residential Aged Care (YPIRAC) initiative was greater awareness by RAC providers of the risks they face in accepting a younger person without adequate additional resourcing.

These people often require regular nursing support and other health services that are rarely available within aged care, disability or community services in any jurisdiction.

As a result, they end up living either in healthcare facilities because of the inability of the disability or aged care system to deliver a comprehensive single system response; and also because the necessary health supports are only delivered in institutional healthcare settings.

In this respect, aged care and more latterly the health system, are continuing to operate as a safety net for the disability system in a long chain of cost shifting between jurisdictions.

The Queensland Public Advocate summed it up well in 2013, stating

The response to people with ABI in Queensland is characterized by a 'bed

> *blocked' system with a 'ripple effect' of subsequent consequences both economically for the state and personally for individuals who do not get access to the crucial rehabilitation they need following a catastrophic injury. Many places that were intended as slow-stream rehabilitation services have unfortunately become long-term destinations with many people residing in these services for 15 to 20 years. This prevents these facilities from operating as short-term rehabilitation services, services that are sorely needed in Queensland.*
>
> *Many people with ABI now 'live' in facilities that were meant for intensive short term rehabilitation with others residing in acute hospital beds and mental health services. The bed blockages in the rehabilitation services (or downstream blockages) mean that pressure starts to build up in acute hospitals to the extent that the next wave of people with ABI have nowhere to go once the acute phase of their care has passed. This creates a situation where many people with ABI are discharged from hospital into the care of their families without appropriate rehabilitation or support. They may also be discharged into aged care facilities.*
>
> *A by-product of not receiving appropriate rehabilitation support and/or being discharged to inappropriate environments is the potential for readmission to acute care facilities, or institutionalised models of support being implemented to address the gap between a person's needs and the available levels of care.*
>
> *These bed blockages have serious impacts, both economically for the public health system and for the long-term recovery and rehabilitation of individuals with ABI.*[22]

RAC providers are now acutely aware that they risk non-compliance and significant penalty under the Aged Care Act if they cannot meet the younger person's needs through the aged care funding structure.

Recent reforms to the aged care system have also made accepting a younger person more difficult for RAC providers. The *Living Longer Living Better* aged care reforms now require RAC providers to actively support the needs of every resident of a nursing home, including younger residents. The Specified Care and Services Schedule outlines the items that are required to be provided - despite cost - to nursing home residents.[23] As well as provision of costly customised equipment, there are numerous areas within the schedule that would be applicable to a younger person including, for instance, social connectedness.

Yet providing social connectedness for a younger person is likely to involve significantly greater costs than it might for an older person. A younger person is, for

[22] Office of the Public Advocate, *People with intellectual disability or cognitive impairment residing long term in health care facilities: Addressing the barriers to deinstitutionisation*, Brisbane, 2013: ix.
[23] For further information, see the *Quality of Care Principles 2014* at http://www.comlaw.gov.au/Details/F2015C00075/Html/Text#_Toc409692213 Accessed 6 February, 2015.

example, highly likely to want to leave the nursing home to maintain contact with family and friends in the community. Transport costs, attendant care costs to support the individual in the community as well as the costs of other amenities, will need to be met in greater amounts than may otherwise be the case for an older person.

Despite their imperative for aged care providers to source additional avenues of income as well as provision of residential support to frail older Australians, the *Living Longer Living Better* reforms now provide another reason for RAC providers to refuse a younger person unless funding and service contributions from other programs, such as disability and health, can be assured.

The inability to discharge medically stable patients with disabilities because of a shortage of appropriate accommodation; a lack of adequate funding to meet assessed needs; or a lack of capacity by service providers to meet their complex needs, results in these young people becoming high cost, long stay hospital patients with poor quality of life. The Productivity Commission estimated that the annual cost to hospitals of long stay patients was between $38 million and $84 million.[24]

In summary, each person in the YPINH cohort has acquired a disability predominantly as the result of an adverse health episode. The common denominator across both YPINH groups is the need for ongoing clinical and other health interventions to sustain recovery from injury or disease exacerbation; and maintain health and well being over the long term.

These health interventions can include specialist pressure care, rehabilitation, customised equipment, behaviour support, PEG, catheter and tracheostomy care. Unfortunately, such clinical interventions are not the province of disability services. Nor are they easily available through health services in the community. Because normative practice is to deliver health services in a health facility; or provide disability services through a disability services program, the opportunity to receive both types of services in a coordinated fashion is, unfortunately, all too rare.

The lack of access to clinical and other health maintenance services (particularly rehabilitation) means that, despite aged care's lack of resourcing to adequately support these young people, residential aged care has become the default placement option for young people with complex health and other support needs

Because eligibility for aged care services for younger people is assessed via the same Aged Care Assessment Tool (ACAT) that assesses eligibility of frail older Australians for aged care services, the Aged Care Assessment processes undertaken in the States and Territories cannot fully capture all vital diagnostic information and are unable indicate the full suite of support responses YPINH may require should they be admitted to RAC.

[24] Productivity Commission 2011, Disability Care and Support, Report no. 54, Vol 1, Canberra: 143.

As a result, available data on YPINH is generally poor, making it difficult to capture the breadth of issues these young people confront; or to inform solutions to the challenges of delivering key services to this group.

Appendix B

Why do young people enter residential aged care?

Young Australians enter residential aged care essentially because of the human services system's failure to deliver the supports and services they need; and because the health services they require to maintain health and well being are not available in community settings. The following distinct issues drive entry into residential aged care.

Chronic systemic lack of capacity and inadequate support provision

In concert with a lack of clinical services that can be delivered in community settings, one of the main causes of younger people being placed inappropriately in residential aged care is the 'across the board' shortage of community based support and specialist disability residential services.

This systemic incapacity is played out not only in the incapacities of the tightly rationed disability and health systems' various service offerings, but also in their inability to work together to provide coherent and integrated supports to the YPINH group.

With disabilities acquired predominantly as a result of catastrophic injury or development of progressive neurological diseases such as Parkinson's and Huntington's Diseases, Multiple Sclerosis and dementias including Young Onset Dementia (YOD), these young people have intense and complex health conditions that require daily care and a range of specialist interventions as part of their management. Data from aged care providers indicates that the majority of younger residents are categorised as high dependency and include a large number of people with high needs without speech who are particularly at risk.

The evidence suggests that there is considerable unmet need for different types of disability supports. According to Victorian Attorney General's Office, as cited in the Productivity Commission report, there were around 1,370 people waiting for supported accommodation in Victoria in 2008, with some waiting lists stretching beyond 10 years. Meeting this level of unmet demand would require the supply of supported accommodation to increase by 30 per cent.[25]

The current state-based disability systems that exist across Australia have largely not been designed to meet the needs of people with the mix of health and disability support needs those in the YPINH group present with. The suite of services currently offered has been developed historically around a different group of people with primarily congenital and developmental disability. By diverting the YPINH group to

[25] See Victorian Auditor General, *Accommodation for People with a Disability* No 85 (Session 2006-08), March. Quoted in Productivity Commission, *Disability Care and Support*, Report No 54, Canberra, 2011: 126.

the aged care sector, the disability system has avoided developing the capacity to support the different needs YPINH present with. This is also something that the National Disability Insurance Scheme (NDIS) must grapple with as it rolls out.

The inadequacies of the current system, due in part to chronic underfunding, mean that it does not generally account for people's future needs. Long delays in service provision often result in avoidable ill health, which in turn results in unnecessary presentations with trauma and other illness to tertiary hospital emergency departments (sometimes with an associated admission). Such delays also result in reduced independence and participation in the community as well as feelings of depression and helplessness.

The need for timely and effective hospital discharge

> ***Lars' story***
> Lars has progressive MS and was hospitalised with a urinary tract infection. His basic council home help services could no longer safely support his needs and in the absence of available disability funding, he was unable to be safely discharged. After 9 months in a sub acute facility, his ongoing deterioration and lack of contact with social networks resulted in Lars becoming extremely depressed and he was discharged to a nursing home without any additional funding or service input from health or disability services. His high and complex needs were unable to be effectively managed by the nursing home's resources and he was admitted again to hospital with aspiration pneumonia. He has had numerous hospital episodes since and his family are now coming in to the nursing home to provide "top up care" 7 nights a week, meal assistance, personal care and social contact. Despite an application to Disability Services, Lars has not received any disability funding or other service input.

The need for hospitals to discharge young people with disabilities who are medically stable, is one of the biggest drivers of younger people entering nursing homes. The case mix funding approaches many acute care settings are now required to operate under, mean hospitals are penalised financially if they do not achieve discharge in a timely and required manner.

As well as case mix funding pressures, the demand for hospital beds by the sick and injured is growing. Hospitals can ill afford to spend scarce health dollars providing long term accommodation for medically stable young people with disabilities.

For the younger people who remain as long stay hospital inpatients, significant risks attend. These include not only the risk of institutionalisation and loss of function, but a very real risk of developing drug resistant infections like MRSA (methicillin resistant Staphylococcus aureus) or VRE (vancomycin-resistant S. aureus).[26] For those individuals requiring slow stream rehabilitation, long stays in hospital also act to

[26] See Medew, J. "Hospital stay is a health risk", *The Age,* Melbourne, 29 August 2011.

deny access to crucial longer term rehabilitation services and effectively compromise recovery from injury or disease exacerbation over the life course.

By the time discharge to aged care is effected – if a RAC provider willing to accept a younger person can be found – the individual's well being will have been compromised; and their capacity to recovery from an injury or disease exacerbation episode will have been similarly diminished.

The number of long stay hospital patients provides further evidence of unmet need for disability supports. Longer stays than necessary in hospital result from a lack of appropriate disability supports, such as supported accommodation, home modifications or appropriate transport.

The inability to discharge medically stable patients with disabilities because of a shortage in appropriate accommodation also results in costly bed-blocking. The Productivity Commission estimated that the annual costs to hospitals of long stay patients were between $38 million and $84 million.[27]

Poor design of injury compensation systems

Carl's story

Carl has lived in a Queensland long stay healthcare facility for the last 12 years. He sustained a brain injury at age 21 in a vehicle accident. He could not attribute fault in the accident and therefore was ineligible to claim for compensation from the Queensland CTP scheme. As a result, Carl was denied the clinical and rehabilitation services he needed to recover from his injuries. These services were simply not available in the public health system to him.

This denial of rehabilitation has effectively prevented him from achieving maximum recovery. He moved to a health facility for rehabilitation, however did not receive any programs. An attempt was made to refer him to aged care, but he and his family refused to leave. He remains in the facility, nearly 13 years later.

He has had to have tendon release surgery on both feet and his right hand because of contractures, which could have been prevented with regular physiotherapy. A privately funded hydrotherapy program is his only regular activity.

Carl's immediate and future housing options are uncertain, as there have been moves to close the facility where he lives. He remains in the facility with little hope of the life he wants, but with renewed pressure from the state health system to move into aged care.

If he had been injured under different circumstances, he would have had the rehabilitation he needed and would be living in his own home.

Although there is now a commitment by Australian jurisdictions to reform personal injury insurance arrangements as part of the National Injury Insurance Scheme,

[27] See Box 2.3, Productivity Commission, *Disability Care and Support*, Report No 54, Canberra, 2011: 143.

poorly designed fault based motor vehicle CTP systems and gaps in cover for other injury causes have seen many people enter aged care because they cannot access any other funded support option.

As one example, the scheme run by Queensland's Motor Accident Insurance Commission requires proof of negligence against the owner or driver of the motor vehicle concerned to sustain claims for compensation and is representative of fault-based schemes that allow young people to languish in residential aged care settings without hope of recovery or rehabilitation.[28]

Breakdown of informal care

Together with the urgencies that attend hospital discharge, the failure of informal care provided by dedicated family members is another key reason for entry of younger people to RAC.

For those with neurological diseases, the progression of that disease commonly leads to one of two scenarios. In the first, informal care delivered at home becomes unsustainable because of the breakdown of the family caregiver's health and subsequent inability to care. The ensuing crisis results either in a fast track entry to RAC or emergency hospitalisation followed by subsequent placement in aged care.

In the second scenario, a younger person will enter hospital to deal with an episode of disease exacerbation. Once medically stable, the hospital looks to discharge to the individual's home. Where the disease episode has resulted in the individual's further debilitation and higher levels of care need, the hospital will contact disability services for a larger funding package to deliver this care.

Disability services chronic underfunding means it cannot respond in a timely manner to such a request, if it can respond at all. With pressure to discharge and a lack of response from disability services, the hospital's duty of care prevents it returning the younger person to their home if inadequate care remains in place. The result is an express route into aged care, even if the younger person does not actually need the higher level of care residential aged care can provide, but could safely have returned home with a modest increase in funding – should that funding have been available.

[28] Queensland operates a common law 'fault' based Compulsory Third Party (CTP) scheme, first introduced in 1936. The scheme provides motor vehicle owners with an insurance policy that covers their unlimited liability for personal injury caused by, through or in connection with the use of the insured motor vehicle anywhere in Australia. For the injured third party it provides access to common law, that is, the injured person has a right to approach a law court to seek monetary compensation from the person 'at fault' for the personal injury and other related losses. As a fault based scheme it requires proof of liability, i.e. the injured party must be able to establish negligence against an owner or driver of a motor vehicle. Consequently, circumstances can arise where, for example, a driver who is wholly at fault in an accident cannot obtain compensation because there is no negligent party against whom a claim can be made. See http://www.maic.qld.gov.au

Inability of disability service providers to manage the complex health and other support needs of YPINH

Mark's story
Mark was diagnosed with Multiple Sclerosis when he was in his late teens. Now a father of two young children, Mark lives with his wife and children in their family home that was adapted several years ago to accommodate his mobility needs. As Mark's disease has progressed, he has needed higher levels of support and allied health input to maintain his capacities and to support him during his disease progression. The unwillingness of the disability system to increase Mark's funded support as his needs have changed and as care agencies have increased their fees each year, has meant that he is at ever escalating risk of placement in a nursing home or a residential disability service. Because these residential services cannot accommodate family units, Mark would be forced out of his family should he have to enter residential care. This is something he wants to avoid at all costs. Although his family is his priority, Mark is also concerned about his ability to maintain his community networks if he is forced into a residential setting.

Australia's disability service system has evolved around the needs largely of those with congenital and developmental disability. It has not been designed to fully understand and meet the needs of people with a mix of health and disability support needs such as those in the YPINH group. While services such as attendant care and equipment are utilised by the YPINH group, the bulk of services offered through disability services programs, such as day programs, the majority of residential services or Australian Disability Enterprises, are not relevant to their needs or choices.

It is the service system's enduring inability to support these young people in the community that comprises one of the reasons young people continue to enter aged care nursing homes. A number of these young people have families with children, so when they are faced with placement in residential services that are fundamentally designed for singles, there is a lot to give up. However these referrals are made to these poorly designed residential services with without even a token consideration for the impact on the individual's family or friends.

Historically, disability service providers have not been required to deliver health supports in addition to disability services and supports. Poor understanding of the complexity of need YPINH present with, alongside the lack of nursing or allied health services in disability residential services, have been factors in the movement of people from disability services to aged care. (This was a driving rationale for the Commonwealth Innovative pool in 2001).

This situation did not change markedly under YPIRAC. While nursing was funded in a very limited number of YPIRAC services, most were standard disability residences.
Over the 5 years of the YPIRAC initiative's operation, the Alliance received many calls

from younger people who had relocated to one of the new YPIRAC disability residential services from aged care, asking how they could return to the nursing home because they felt unsafe in the new service and lacked confidence in the ability of the provider or the staff to competently support their needs.

We are also aware of instances in which the complex health needs of the younger people they accepted from RAC, was beyond the capacity of disability service providers and their staff to support. When emergencies occurred, such as aspiration pneumonias from poor management of PEG feeds or inability to manage indwelling catheters, the common response was for an ambulance to be called and the individual admitted to hospital to resolve the emergency. In a number of these cases, after several emergencies and hospital admissions, the disability provider refused to take the younger person back from hospital because they were "just too hard" to manage.

Poor compatibility and connection between health, disability and aged care sectors

If young people in the YPINH cohort are to sustain health and wellbeing and live in community settings, their health needs particularly require active collaboration and service coordination across disability and health service sectors.

The language and systemic imperatives for the 3 sectors are very different; and there is a very poor understanding of how each works by the other. Where there is a systemic clash of interests between the sectors, such as those involving Occupational Health and Safety (OH&S), clinical indications, need for speed in discharge, risk management, lack of knowledge, responsibility shifting, no available funding or capacity in the disability system for hospitals to discharge, aged care is often the default option and the real needs of a person can be overlooked in order to satisfy the system's requirements.

From the Alliance's work, we strongly believe that developing cross sector service coordination is imperative if the health and social outcomes needed by YPINH are to become a reality. Programs in health, housing, disability and sometimes aged care, must work collaboratively to deliver their several service offerings so that the full suite of services these young people require can be delivered through integrated care pathways.

As was the case prior to YPIRAC, the reality of long stay hospital patients with disability is an intensifying problem across the jurisdictions (along with older residents in the same situation). Solutions to this are thin on the ground, mainly because viable solutions lie outside the health sector and the ability to work collaboratively with disability or aged care is limited.

At a national level, the federal Department of Ageing continues to lament the placement of younger Australians in residential aged care services (RAC) but does nothing to develop more collaborative practices with its jurisdictional partners that might address the YPINH "problem" from a more systemic perspective. As a result

and precisely because of the more than 6,500 younger Australians living in nursing homes, the Department of Ageing remains the third largest funder of disability accommodation in the country.

The aged care, health and disability systems remain largely incompatible on a number of levels.

- Hospitals only do 'in reach' allied health consultancy into aged care facilities for residents following discharge from an episode of acute care. Younger residents require longer term input, but these programs do not provide this.
- The aged care co-payment model for capital and services is fundamentally different to the means test free disability system. A younger person caught with additional financial burden because they are forced into aged care due to the incapacity of the disability system, creates a clear anomaly.
- Standards are different across programs. For example, an aged care provider only needs to acquit aged care standards, not disability standards, despite the latter being more relevant to younger residents. Even where aged care providers have had top-up packages from disability service programs (whether through block funding or through individual packages) there has not been any requirement for the aged care provider to acquit their services against the disability standards. While doing so would create administrative costs for providers, the different expectations of the disability system need to be reflected in the standards framework in aged care.
- The aged care workforce is generally not equipped to meet the needs of younger residents as, naturally enough, the industry training models concentrate on the care of frail older people. The structure of rosters and staffing levels in residential aged care as well as the increasing size of facilities also work against a highly individualised response to younger residents. This is not something that aged care providers set out to do, but is a consequence of their funding and industry constraints. Despite an inquiry into the adequacy of its funding regime, the Aged Care Funding Instrument (ACFI) remains unable to fund the supports the YPINH cohort require if they are to live in residential aged care.