



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

**Submission by the
*Young People In Nursing Homes National Alliance***

April 2013

1. Introduction

The Young People In Nursing Homes National Alliance welcomes the opportunity to provide a submission to the Senate's *Inquiry into the Living Longer Living Better Aged Care Bills 2013* including

- Aged Care (Living Longer Living Better) Bill 2013
- Australian Aged Care Quality Agency Bill 2013
- Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013
- Aged Care (Bond Security) Amendment Bill 2013
- Aged Care (Bond Security) Levy Amendment Bill 2013 (the Bills).

The Alliance recognises the aged care reform intentions and largely supports the introduction of the *Living Longer Living Better* aged care reform package, as far as it relates to younger residents.

It is important to say at the outset that as an issue, younger people in aged care (YPINH) has never been a good or an easy 'fit' – both at an individual and a policy level. Despite the YPINH group occupying nearly 5% of residential aged care places and receiving high profile community attention, the aged care system continues to ignore this group at a policy and funding level because, despite their presence in the aged care system, YPINH have historically been defined as the responsibility of the disability program area.

While we recognise that these bills are not specifically targeting the 5% of aged care places occupied by younger people, we also believe that unless the YPINH issue is formally recognised as important part of the aged care system, it will continue to create problems for aged care providers and compromise the lives of thousands of Australians.

While disability services reform through *DisabilityCare Australia*, promises to resolve many of the issues YPINH face in the future, the Alliance believes that, due to other systemic incapacities, younger people will continue to be a small but prominent feature of the aged care system for some time to come.

Our submission draws on ongoing consultation with young people in nursing homes and their families, as well as a range of organisations. These include organisations advocating for younger and older consumers; disease specific groups and networks; state and territory peak consumer organisations; service providers in aged care, health and disability; and individual consumers, their families, carers and social networks. Recently these discussions have also included comment about the interface between the National Disability Insurance Scheme (*DisabilityCare Australia*) and the aged care system.

The central concern expressed about this interface is the strict 65 year age cut-off

for eligibility of *DisabilityCare Australia* that is defined in its legislation. This issue was canvassed extensively in the Community Affairs Legislation Committee's *Inquiry into the NDIS Bill 2012*, by a number of organisations. This age exclusion means that the aged care system is now structurally responsible for the full care of people who acquire complex disability over the age of 65. This includes people with acquired brain and spinal cord injury, motor neurone disease and other degenerative neurological conditions.

The specialist services that are required for these people mostly exist in the disability system and it is unclear how people outside *DisabilityCare Australia's* remit can either access these through the aged care system; or alternatively, receive duplicate supports from the aged care sector that have the same capability and scale as those provided to people with the same conditions, but under 65 years of age.

The practical reality of this question will be observed and evaluated in the *DisabilityCare Australia* launch sites in NSW and Victoria. But we believe that this boundary requires the current suite of bills to expressly provide the aged care system with improved capacity to deal with people with non-age related disability as a matter of urgency.

Quite apart from the *DisabilityCare Australia* interface (which will not be systemic until 2016 at least in most jurisdictions), there are real issues now with the aged care system's recognition of, and capacity to deliver quality services to, younger people with complex disability. These issues need to be addressed in the current bills.

Rather than the age at which it is acquired, it is the response to disability that is the critical issue here. Unless the same suite of responses is available to people on both sides of this age cut-off, then a serious inequity exists that will go unresolved. This will express itself not only for the individual with disability in the aged care system, but for providers too who already struggle to meet the aged care standards where their younger residents with disability are concerned, because of the capacity constraints they face.

In addition to this main issue, our members have consistently raised the following related concerns throughout our consultations:

- The care management of younger people in aged care, particularly for those with complex health conditions
- The capacity of the aged care sector to manage the social and lifetime support needs of younger people with significant disability
- The funding arrangements *DisabilityCare Australia* will enter into with residential aged care providers to support clients of *DisabilityCare Australia* at full scheme implementation and in launch sites prior
- The need for appropriate support and accommodation arrangements for younger people who may use Residential Aged Care (RAC) as an interim

option before transition to the community.

This submission addresses these concerns.

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 clinical 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.

The Alliance's membership is drawn from all stakeholder groups including YPINH, family members and friends; aged care, health and disability service providers and peak 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 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.

From its inception, the Alliance has partnered with aged care providers to develop solutions to the YPINH issue. The Alliance believes that residential aged care will remain one of the ‘options on the spectrum’ for younger people with high and complex clinical needs for some time to come, whether as a transition or longer term option.

DisabilityCare Australia’s advent and the resultant move to place all individuals who acquire profound disability after 65 years in the aged care system only, also means that the aged care system will confront profound disability more regularly perhaps than it presently does.

3. Young People In Nursing Homes (YPINH)

There are approximately 6,800 younger Australians living in residential aged care, occupying a significant 5% of aged care beds nationally. There are also a considerable number of people with complex disability living in the community with inadequate support and fragile care arrangement who are at risk of placement in residential aged care if the service system remains unable to respond to their needs.

One of the main causes of younger people needing to be placed inappropriately in residential aged care is the severe shortage of community based support and specialist disability accommodation services across the board. This systemic incapacity is played out not only in the (in)capacities of the tightly rationed disability support and health systems’ various service offerings, but also in their (in)ability to work together to provide a coherent and integrated support to this 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 dementia’s including Young Onset Dementia (YOD), it is well documented that the YPINH group need a joined up service response from health, disability and aged care services to meet their clinical and other support needs, something the population breakdown of young people in nursing homes group with acquired disabilities demonstrates:

- *Acquired Brain Injury (ABI)* 30%
- *Physical Disability* 27%
- *Neurological* 23%
- *Intellectual/psychiatric* 20%¹

And where data received from aged care providers indicates that the majority of

¹ See *The ABI Strategic Plan*, Victorian Department of Human Services, Melbourne, 2001.

their younger residents are categorised as high dependency,² recent studies have also concluded that

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

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

3.1. YPINH and Disability Services

Evolving historically to respond to the needs of those with more predictable types of congenital disability, the Disability Services system managed by the states and territories exists in a state of chronic underfunding. In undertaking their responsibility for delivering disability services, the states and territories take a demand management approach to requests for assistance and maintain service needs registers to record those requiring assistance. In an attempt to be 'equitable', Disability Services' responses are allocated to those who have been identified as the most critical urgent current need on waiting lists, not necessarily those who require pro-active and preventative supports to maintain them with their families and communities.

Disability Services programs (such as attendant care, equipment and community integration) are designed to be non-clinical community supports to address the particular needs of the traditional population of people with disability. These programs have not developed expertise or capacity to cater to the complex needs of the YPINH group on its own. (There are small diagnostic specialist services for people within the YPINH group in some States, but they do not have universal coverage.)

As a result, Disability Services funding and service delivery environment continues to struggle to meet the requirements of those with changing needs. Disability Services' funding limitations and its design of its funding rules thus means that it continues to struggle to access increasing levels of service in a timely manner.

As a result, YPINH have poor representation within Disability Services nationally. As one example, ABI was the primary disability group of close to half (46%) of all

² Of a total 6,505 residents under 65 in June 2006, the majority or 4,911 were categorised as high dependency (RCS 1-4); the remainder or 1,594 were considered low dependency (RCS 5-8). *Source:* AIHW analysis of DoHA Aged and Community Care Management Information System (ACCMIS) database. Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4th Edition, Canberra, 2007: 135.

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

*Younger People In Residential Aged Care (YPIRAC)*⁴ service users in 2007–08. This compares with 4% of National Disability Agreement (NDA) service users with ABI as a primary disability group. Two in five YPIRAC service users (40%) had neurological disability with or without another type of disability compared with 13% of NDA service users with neurological disability.⁵

Figures such as these demonstrate the service gap that exists and, while underscoring the need for a better articulated ‘life time care’ approach, also help explain why so many individuals with significant disability and complex health needs arrive at aged care’s door.

Having had an able bodied life before injury or illness that has delivered significant, lifelong impairment means that, as well as different support needs, the YPINH group has different expectations around service responses to those living with a congenital disability. These young people expect to access the rehabilitation, clinical and other support services needed to restore health and independence; and to live in the community as able-bodied young people do.

Because of its age profile and the general nature of residential aged care, entry to RAC not only confounds these expectations but also denies younger people the resources required to meet their recovery or lifestyle needs. Without these specialist resources, RAC service providers are unable to deliver the suite of responses they know their residents with profound disability require and they very much want to provide. While there is overwhelming good will from aged care providers towards their younger residents, they simply do not have the resources to deliver the comprehensive support these residents need.

3.2. Impact of YPINH on aged care services

YPINH usually arrive at the door of the aged care system without warning and typically on discharge from an acute care setting. For acute care discharge planners looking to discharge an inpatient with significant disability and clinical issues, residential aged care has become a default response because of the chronic incapacity of the disability system to provide either a support and/or accommodation response; and the disability service system’s lack of training, skills, expertise and capacity to manage the complex clinical needs these young people usually present with.

In fact, since the end of the *Younger People In Residential Aged Care (YPIRAC)* initiative in 2011, the Alliance has observed a concomitant, rapid and dedicated escalation in the numbers of younger people entering RAC. Where prior to YPIRAC,

⁴ The *Younger People In Residential Aged Care (YPIRAC)* initiative is a 5 year , joint Federal/State program that was intended to be a first step to resolution of this longstanding and entrenched problem. The first tranche concludes in July 2011.

⁵ Australian Institute of Health and Welfare, *Australia’s Welfare 2009. 9th Biennial Welfare Report* of the AIHW, AIHW, Canberra, 2009: 169-172.

disability services would at least attempt to address the needs of these young people, even that is now missing with disability services generally abrogating its responsibility to provide the suite of services it is funded to deliver as part of a state cost shift to federal aged care.

Because of the numbers of young Australians with disability residing in residential aged care services, the federal Department of Health and Ageing remains the third largest funder of disability accommodation in Australia.

Yet the aged care sector has largely evolved to support the needs of older Australians requiring additional support and care as they age, with Residential Aged Care (RAC) services mostly concerned with supporting frail older residents in the end stages of their lives.

Based on an expectation of asset accumulation over a working lifetime that will be contributed to the cost of aged care services used by older Australians, Australia's aged care system expects client co-contributions to help fund community supports such as Home and Community Care services (HACC), Community Aged Care Packages (CAPS) and Equivalent Aged Care in the Home (EACH) and EACH Dementia packages (EACHD); and contribution through bonds of significant value, to enter RAC. While some RACs do not require bonds but depend on government subsidies entirely, all RACs are able to request a contribution of up to 85% of aged care and disability pensions to cover the residential costs they incur.

However, younger residents with profound disability and complex needs have had their capacity to accumulate such assets over a working life cut short. Despite this, the same rules that apply to older residents with assets also apply to younger residents who may have accumulated savings before acquiring a disability.⁶

Similarly and because residential aged care services are resourced to support the particular older demographic they have evolved to support, they are not resourced to provide

- Community or slow stream rehabilitation services
- Customised equipment including electric wheelchairs; high end pressure care; and assistive technologies such as communication devices
- Community access
- Transport costs and a worker to accompany an individual into the community.

These structural realities create considerable problems for individuals with profound disability and complex health needs resident in aged care nursing homes. Of particular significance is the fact that RAC does not have mandatory minimum staffing levels. This one item alone causes enormous dislocation and difficulty, not

⁶ In this regard, see Marie's case study provided at the end of this submission.

just for the severely disabled residents dependent on inadequate staffing to respond to their needs, but also for the aged care staff who support them without the resources they know are required.

Younger people are usually bigger and heavier than older people and commonly require two person assists for transfers, repositioning in bed or chairs or to go to the toilet. Additional assistance at mealtimes can be hard to come by and younger residents have sometimes been placed on PEG feeds in an attempt to deliver adequate nutrition in the presence of inadequate staffing levels.

It is a fact that without the staffing levels and dedicated input needed to provide these various supports, younger residents routinely lose vital life skills that are extremely difficult – and expensive – to regain, should they have opportunity to move to the community. Specific issues such as behaviour management, continence, skill development and social isolation are extremely challenging for providers and ultimately these younger residents miss out or are marginalised due to the absence of specific supports.

For the aged care service concerned, a resident with profound disability can create enormous structural and financial problems. One of the results of the YPIRAC initiative was a greater caution by aged care providers in regard to accepting younger residents with profound disability and complex health needs.

When approached to take a younger resident today, most residential aged care providers will refuse unless the significant resourcing shortfall is addressed through funding from Disability and/or Health Services on discharge from acute care. The Alliance is aware of numerous instances in which the nursing home concerned has requested a signed contract outlining the contributions from Disability Services particularly that will be provided over the course of the resident's time in the nursing home.

However, this is not the usual practice of Disability Services programs whose working knowledge of aged care is poor. Apart from the YPIRAC program, they do not routinely deal with aged care providers and have been reluctant to engage in such joint funding agreements.

4. The care management of younger people in aged care

Whether individuals are over or under the age of 65 years, the aged care sector is clearly not resourced to adequately support those with significant disability; or offer the same type of supports that would be available to individuals in the Disability Services' system. Nor does the aged care system have capacity to offer the types of slow stream rehabilitation those with profound acquired disability commonly require, but are presently unable to access from either disability or health services.

While the advent of *DisabilityCare Australia* will provide funding for the suite of supports and services those under 65 years in RAC require, the intervening six years before the scheme comes to full operation means that many younger people under 65 years in RAC will not receive the supports and services they need if they rely on aged care alone.

Similarly, individuals acquiring profound disability *after* the age of 65 years will not be able to call on the *DisabilityCare* scheme for assistance, having to rely instead on an aged care system entirely unable and unprepared to meet their complex needs.

A case in point is that of Geoff Haigh. Geoff was an active man who took a daily morning walk before starting his demanding job as the director of special projects with Queensland's Department of Transport. But on February 6th last year, he fell awkwardly, broke his neck and is now an incomplete quadriplegic, able to move his arms but not his hands. The accident happened only three months after his 65th birthday.⁷

Because the aged care system's entitlement begins at 65 years, Geoff is technically within its remit. As he has found out, however, this means he receives a vastly different type and quantity of care than he would have received had he been injured prior to his 65th birthday and fallen within Disability Services' parameters. Instead of the up to 65 hours per week of support Disability Services would have delivered, Geoff is reliant on a maximum of 15 hours from aged care services and the support of his wife to make up the shortfall.

Geoff requires significant assistance and customised equipment as well as ongoing allied health supports to maximise his capacity. These are supports aged care does not presently provide. Should he move into RAC, the situation will be compounded by the severely rationed services and supports available in a nursing home for someone with his level of need and relative youth.

Should the informal care now provided by his wife cease and Geoff enter a nursing home, his comparatively young age means that not only will he be one or two generations younger than older residents, but he is likely to remain there for many years more than the average of 6 months to 2 years commonly expected by residential aged care services now.

5. *DisabilityCare Australia's* funding arrangements with RAC providers to deliver care and support to Scheme clients

Despite the welcome advent of *DisabilityCare Australia*, this national scheme is an evolutionary entity. In its current incarnation, it is necessarily focussed on disability

⁷ Geoff Haigh's story was the subject of an ABC Radio PM story that aired on January 22 2013. The transcript can be accessed at <http://www.abc.net.au/pm/content/2013/s3674407.htm>

and disability services as it moves to bring the first groups of individuals online through state based launch sites.

It is likely that the *DisabilityCare Australia* will fully fund younger people in RAC and not just back-fund the Aged Care Funding Instrument (ACFI) bed fee. Individual packages for YPINH may include the full suite of disability services, including equipment, allied health, personal and community support, community access and so on. But just what services and supports the scheme will fund and to what degree, remains to be seen.

So too, the scheme's capacity to interrogate and involve Aged Care and Health as well as Disability Services in determining service responses for its clients in RAC remains unclear. The impact of this expanded funding and provision of needed services and supports into RAC and how this will impact the aged care provider is also unknown.

In the interim, Aged Care services should take steps to establish collaborative partnerships with *DisabilityCare Australia* and with Health services so that the integrated service responses that young people with complex health needs require in RAC, are developed.

Doing so will not only benefit the individuals who need this skilled integrated response. It will also deliver clear cost benefits to aged care, health and disability services and potentially lead to development of a new suite of service responses for individuals with this level of complex health and other needs, whether over or under 65 years of age.

The interim before the *DisabilityCare Australia* Scheme comes to full operation offers a significant opportunity to prosecute improved partnerships and collaboration between the three program areas mentioned in this submission; and undertake 'proof of concept' trials that have potential to "lay the groundwork" for the integrated pathways *DisabilityCare Australia* will need for its clients with complex needs in the future. The development of such integrated service pathways also fits neatly within the aged care reforms currently underway with their focus on "reablement" and a person centred approach.

In an attempt to define and better understand how these relationships and joined up service pathways might operate, the Alliance is currently working with aged care providers, health networks, disability services and individuals with complex health needs to explore practical service responses involving input from all three program areas.

In doing so, we believe that integrated service responses, such as the ones this submission has described, are not just the preserve of those with complex needs

but, as a 'whole of life' concept, are service responses that any Australian with impairment will want and expect to access, regardless of age.

6. Integrated service responses for individuals with complex health needs in RAC

From the Alliance's work across Australia, the incidence of individuals with acquired and profound disability entering residential aged care since the end of the YPIRAC initiative has grown exponentially. As indicated previously in this submission, these individuals commonly enter RAC on discharge from acute care or from the community because no other option is available.

Despite this growth, there remains a distinct policy void in aged care in regard to the specialised services younger residents require. Even services that are still capable of providing targeted responses are extremely rare. Attempts to join up aged care with specialist disability services have been rare and piecemeal while the funding agreements that govern these sectors (the National Disability Agreement and the HACC Agreement) have looked to divide responsibility rather than share it. The net result has been that significant gaps and process problems continue to define the YPINH issue.

The hard consequence of this blunt response is clear. Young people with acquired disabilities and complex health needs continue to enter an endless merry-go-round of bureaucratic avoidance where various arms of the service system diminish their responsibility for the care and support these young people require, as they actively shift their responsibility to aged care.

Yet it need not be so. The common sense alternative is to embrace an integrated approach that sees each program or portfolio area with a vital contribution to make, collaborating to deliver the coordinated suite of services required. Rather than a single 'arm' of the service system, such as disability, aged care or health being responsible for the entirety of care for an individual with multiple and complex needs, such an approach is built on utilising the significant expertise each program area 'brings to the table' in concert with a portion of the total funding needed.

Managed in this way, the support needs of individuals with complex needs and other co-morbidities can be comprehensively met without any single area having to fund the full quantum required. An integrated approach would ensure that direct services (such as accommodation) could be provided, while companion specialist services such as training, secondary and tertiary consultancy for behaviour and clinical management can be drawn from different areas appropriately.

However, the current 'siloed' makeup of the service system mitigates against such collaboration and partnership. The traditional separation of services delivered by health, disability and aged care programs; the budget constraints that require designated funding from a program area to be spent only within that program's

boundaries; the cost shift that results when a person eligible for state Disability Services is placed in federally funded aged care; Health's view that disability is not part of its remit...all these have made the development of integrated service responses involving these three portfolio areas extremely difficult to develop, deliver and maintain.

Yet when the interfaces between these programs are softened and a 'joined up' service response involving all three is articulated, the results can be dramatic, long lasting and cost effective for all involved.⁸

Clearly, no one arm of the service system can provide the suite of services that individuals with complex health needs require. Disability, health and aged care services each holds a portion of the expertise required to successfully provide the service response appropriate for those with this level of need. Each, therefore, holds part of the solution. All that is needed is for these parts to form a coordinated and collaborative whole.

7. DisabilityCare (National Disability Insurance Scheme, NDIS)

Despite the welcome advent of *DisabilityCare Australia*, this national scheme is an evolutionary entity. In its current incarnation, it is necessarily focussed on disability and disability services as it moves to bring the first groups of individuals online through state based launch sites.

Whether the scheme has capacity to develop and coordinate comprehensive cross program support packages for participants in launch sites that include aged care, health and other community programs, remains to be seen. At the very least and as a matter of urgency, *DisabilityCare Australia* should take steps to establish collaborative partnerships with Aged Care and with Health so that the integrated service responses YPINH need, are in fact developed in the launch sites.

The period in the lead up to the full roll out of *DisabilityCare Australia* offers a significant opportunity to prosecute improved partnerships and collaboration between the three program areas mentioned in this submission; and undertake 'proof of concept' trials that have potential to "lay the groundwork" for the integrated pathways *DisabilityCare Australia* will need for its clients with complex needs in the future.

⁸ See the Continuous Care Pilots undertaken in Victoria and NSW as part of the Younger People In Residential Aged Care (YPIRAC) initiative. These small pilots used coordination of services and a risk management approach to deliver the integrated responses pilot participants utilised. Amongst the benefits of this approach were significantly reduced hospitalisations (the NSW scheme paid for itself through savings delivered by pilot participants' reduced hospital admissions); improved health and well being in pilot participants able to access much needed Health and Disability Services in a timely manner; family breakdown significantly reduced with attendant social services cost savings, et al. Both the NSW and Victorian CCP Reports can be accessed at <http://www.ypinh.org.au/reports>

The development of a care and support pathway for the YPINH group is not only critical for *DisabilityCare Australia* in the future, but for YPINH who are in the system now. This pathway is more than just about funding responsibility, but should define the various specialist contributions of the health, disability, housing and aged care sectors. The Department of Health and Ageing should be a partner in developing this pathway as it concerns sectors that it funds and regulates.

DisabilityCare Australia will be the primary funder of YPINH in the future and aged care providers – rather than being forced to simply offer a standard aged care response to their younger residents – will become providers for *DisabilityCare Australia* for those under 65 years in RAC.

Until the scheme is fully operational (estimated to be mid 2019) there is still an imperative to focus on the key policy and practical support issues for YPINH outside the launch sites.

Doing so will not only improve the lot of those younger people under 65 years drawing on aged care's support. It will also offer opportunities for aged care providers to better support residents who acquire their disability post 65 years and for whom *Living Longer Living Better* is their only option.

Contact

For further information or comment about this submission, please contact

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8. Case Studies

8.1. Marie

Marie is a single mother with four children ranging in age from 4 to 17 years. The two oldest are stepchildren Marie has raised alone since her husband's departure.

Marie became HIV positive not long after marrying her African husband who was HIV positive, though non symptomatic. He did not disclose his condition to Marie and Marie's youngest child has now been confirmed as HIV positive.

After her diagnosis, Marie preferred to continue raising her family, relying on alternative therapies rather than the cutting edge drugs commonly prescribed for this condition. As a result, Marie managed to raise her children until recently when she suffered a complete system collapse from the disease.

Some 3 months after she entered hospital and with stable health, the hospital was keen to discharge. Marie's needs were well beyond those state Disability Services could support and the latter had no systemic capacity to do so any way. The hospital began looking to aged care for a response.

Over the ensuing 12 months, Marie's parents employed a specialist consultant to investigate and broker an arrangement with an aged care nursing home to take Marie. But despite approaching over 30 aged care providers, only one nursing home was willing to accept Marie and that was with reluctance because of the complexity and intensity of her needs.

After more than 12 months in an acute care setting, Marie was finally discharged to a residential aged care service. She had been denied rehabilitation as the hospital was of the view that she would not be able to take advantage of hospital based fast stream rehab services. She was unable to speak and suffered significant cognitive impairments as well as a range of other high and complex health needs that, despite its best efforts, the nursing home struggled to manage.

As one example, Marie's double incontinence often required complete clothing changes and showers two or three times daily. Yet the nursing home had a limited number of shower chairs that had to be shared by all its residents. This, together with aged care's lower staffing levels, meant that Marie had to wait for two staff to be available to attend to her personal care and do so only if a shower chair was available.

Marie also ran up against another inequity commonly suffered by younger people in RAC. She had managed to save an amount of \$17,000 that was to support her four children's education. Yet on entry to aged care, she became subject to the same

aged care rules that make it possible for a portion of any assets (including savings) to be contributed toward the cost of the aged care bed.

Despite many representations, her children's education funds were progressively used as a co-contribution to Marie's aged care placement until Marie relocated to a specialist community supported accommodation service nearly a year later.

While the nursing home had taken Marie in an effort to assist, they decided that their lack of adequate resourcing to support her needs had drained their resources; distressed their staff who were unable to provide the care they knew Marie needed; and caused them to use resources that should have been allocated to their older residents. As a result, the nursing home's management decided not to take a younger person with that level of disability again.

8.2. Sienna

Sienna is a 30-year-old woman diagnosed with Young Onset Dementia. As well as YOD, Sienna has a number of additional medical conditions that complicate and accentuate her YOD. These include mitochondrial disease, epilepsy, an acquired brain injury and a mild intellectual disability.

Her parents have cared for Sienna at home, all her life. They have had minimal disability funding, input and support. What they have received from Disability Services and Home and Community Care Services (HACC), has been provided predominantly as respite and minimal home services for Sienna's parents.

Their advancing age and the development of challenging behaviours in their daughter that they have been increasingly unable to manage, has meant Sienna's parents have reached the distressing conclusion that they can no longer adequately support their daughter themselves. As a result, they have been looking for a suitable supported accommodation service for her near their family home.

After approaching state Disability Services, they were informed that there were no vacancies in disability supported accommodation services at that time and that it was unlikely a vacancy would arise in the short or medium term. They were also informed that, with her particular condition, Sienna's needs were beyond the capacity of the Disability Services system to support.

Sienna's parents were advised to look to aged care for a solution and further informed that if their daughter did enter an aged care service, state Disability Services' responsibility for providing funding and support to Sienna, would cease; and that existing services (including equipment) would not follow Sienna into a nursing home.

With no options offered by Disability Services, her parents began looking at residential aged care homes and finally managed to locate a nursing home that was willing to accept their daughter.

Without the training and support nursing home staff needed to understand and support Sienna, the move to the nursing home was a disaster. Within 24 hours of arriving, Sienna had a ‘meltdown’ brought on by the unfamiliar surrounds of the nursing home and low sodium levels. With Sienna’s behaviour becoming increasingly aggressive and uncontrollable, she was transferred to the emergency department of the nearest hospital.

In hospital, her multiple medical conditions made it difficult for doctors to make a conclusive diagnosis. As a result, Sienna spent most of the first week being moved between different wards in an attempt to place her in a ward that married with her condition, moves that only intensified her distress and accelerated her challenging behaviours consequently. Eventually, in the face of her challenging behaviours and in the absence of a ward that would accept her, she was placed in a locked mental health ward, a placement that was no more suitable to her needs than the medical wards had been.

Over the four weeks she spent in hospital, doctors struggled to successfully manage her challenging behaviours, with the result that Sienna was “specialled” on a 24/7 basis in the mental health unit. “Specialling” requires 1:1 care and means the person is never left alone.⁹ But despite this, the unfamiliar surrounds and constant changes in routine left Sienna ever more distressed, a distress expressed through even greater escalation of aggressive behaviours to the point where Sienna was physically restrained by hospital security staff.

However, once Sienna’s health had stabilised and the hospital felt it could do no more, the hospital was keen to discharge Sienna to the nursing home without delay. But by this time, the nursing home was much more aware of Sienna’s complex needs and the resourcing they would need to manage them adequately.

Understanding that the resources they required were far greater than those available under standard aged care funding, the nursing home told the hospital that they would require additional funding, either from the hospital or from state Disability Services. In the absence of this funding, the nursing home refused to take Sienna until the funding they needed was in place and staff had received training in managing Sienna’s needs.

⁹ Specialling can cost upwards of \$1000 per day on week days and \$2000 per day on Saturdays and Sundays for 24 hour care. Rates vary according to the state concerned. Rates provided in conversation with Head of Nursing, Western Health Network Victoria. September 2012.

Having been involved with the family in trying to get the community accommodation and supports Sienna needed, the Alliance worked with health, disability and aged care services to broker a joined up discharge response. While the aged care service was willing to take Sienna, they were desperate for funding and other supports to ensure they could manage her needs effectively. Unfortunately, Health and Disability Services initially saw a joined up discharge plan as outside their remit and refused to provide funding and other resources to the nursing home.

As example, the hospital was asked if it would work collaboratively with nursing home staff to share the techniques they had found successful in caring for Sienna. The initial response was that the hospital was concerned with management of acute care only and did not 'do' training for external, non Health services.

Disability Services was similarly reluctant to engage. The common response was that as Sienna was technically in an aged care nursing home, she was no longer state Disability Services' responsibility but that of the Commonwealth through the latter's funding of aged care. The fact that the aged care service did not have mandatory staffing levels; that its staffing levels were necessarily below those used in Disability Services; and that the nursing home lacked the resources to manage a younger person with complex needs, was not of concern.

For Health, this enduring stalemate was finally broken when the hospital realised that

- The nursing home would not accept Sienna back without funding and other supports from both Health and Disability Services;
- Sienna was highly likely to re-present at emergency if the move to aged care failed again;
- The nursing home was likely to refuse to accept Sienna on discharge a second time, leaving the hospital to provide indefinite long term accommodation in an acute care bed.

From Disability Services' point of view, the stalemate ended with recognition that commitment of minimal disability 'transition' funding would, in fact, deliver a cost shift to a Commonwealth funded aged care bed and Sienna would no longer be their 'problem'.

At the present time, transition funding, expertise and services have been committed by both Health and Disability Services to support Sienna's discharge to the nursing home. The problem is that when this transition funding expires on June 30 2013, there is no funding or commitment currently in place to continue supporting the nursing home's efforts the next day (July 1 2013) or going forward.

Without this collaboration and commitment, it's almost certain that the nursing home will – despite their very best efforts – be unable to support Sienna appropriately and she will return to acute care at some point after this date. While return to acute care is a less appropriate and much higher cost option that is clearly unsustainable, the absence of a more constructive funding partnership means the state health system will pay a hefty premium while it remains in place.

Yet a 'joined up' response that could deliver a 'life worth living' for Sienna and provide substantial benefits to all the services involved, could so easily be achieved if the three service areas involved would commit to collaborate to the mutual benefit of all stakeholders.