



Office of the Public Advocate Queensland
Inquiry into
People with Disability in
Long-Stay Health Care Facilities

Submission by the
Young People In Nursing Homes National Alliance

August 2013

Key Recommendations

To enable effective discharge of young people with complex health needs from healthcare facilities with an intact suite of services required to maintain their health and well being in community settings, the Young People In Nursing Homes National Alliance makes the following recommendations:

1. *Partnership on integrated service responses.*

Health, disability, housing and aged care services must work together and partner with other portfolios as needed, to develop and deliver the “joined up” support programs required by those with complex health needs in community settings.

2. *Mandate by the Queensland Premier.*

The Queensland Premier to personally mandate and oversight this vital and much needed human services reform to join up key service portfolios to bring about better and more efficient services for individuals with disability and complex health needs.

3. *Early start to discharge planning.*

Discharge planning should begin early in the inpatient process, as soon after diagnosis as possible and not be left to the last moment. Ideally, hospitals would have a good working knowledge and active relationships with the relevant community programs they would need to partner with, alerting these programs to their likely need for involvement as soon after admission as possible. This offers opportunity for other programs to begin working with the health service to understand the needs they may be called on to meet; to undertake their own assessment processes regarding need and availability of appropriate resources; and start planning for delivery of their ‘part’ of the joined up response.

4. *Development of specialist coordinator roles to oversee integrated service responses.*

These coordinators would have a mandate for their cross-program roles from Queensland health, disability, housing and aged care portfolios and be:

- a) Highly skilled, tertiary care coordinators with demonstrated understanding of the different operations and expectations of multiple areas of the human services system
- b) Jointly funded by health, disability, housing, aged care and other programs relevant to the individual’s needs and participating in development of an integrated service response

- c) Mandated by all programs to draw on the programs' several expertise, key personnel and funding to deliver 'joined up' service responses
- d) Located in community agencies
- e) Responsible for the planning and implementation ('directing traffic') of individual programs as well as continuing the monitoring and 'adjustment' of integrated service responses in the community
- f) Responsible for coordination and delivery of provider training and that of support workers in disability and aged care services in management of the complex health needs of residents
- g) The key liaison between programs and individuals.

5. *Partnership with DisabilityCare Australia to develop innovative integrated service responses*

The Queensland Government should develop practical partnerships with DisabilityCare Australia that utilise existing state program knowledge and expertise. This needs to include the development, testing and delivery of cross program 'joined up' service responses that can be utilised by DCA at full scheme rollout.

1. Introduction

The Young People In Nursing Homes National Alliance welcomes the opportunity to provide a submission to the Queensland Office of the Public Advocate's *Inquiry into People with Disability in Long-Stay Healthcare Facilities*.

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.

Over the past several years, we have worked with a number of young people unable to be discharged from healthcare facilities in Queensland, their families and friendship networks as well as departmental and provider representatives from health, disability and aged care agencies. Families and individuals facing placement in residential aged care in Queensland; and those simply unable to access the resources they need to remain in the community, also contact us for help with a range of issues including brokering the disability funding, health and other services they need.

The Alliance believes that partnership and collaboration between health, disability, housing and sometimes aged care, can deliver the suite of services these individuals need to exit healthcare facilities and maintain their health and well being in the community.

2. The YPINH National Alliance

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.

Submission to the Queensland Office of the Public Advocate's Inquiry into People with Disability in Long-Stay Healthcare Facilities, August 2013.

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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.

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

3. The current work of the YPINH National Alliance in Queensland

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

We are currently working with a number of members in Queensland. While it is telling that an organisation travels across two state borders to do so, the model of advocacy used by the Alliance is non-traditional, collaborative and constructive. The specialised nature of the work with the YPINH target group is beyond most advocacy organisations and single-issue agencies. We believe the 'brokered' approach we take forms part of the solution that could be adopted long term; while the skilled coordination role we promote is central to the 'unsticking' of the issues around long-stay patients.

4. People with disability in long-stay health care facilities

4.1. A growing problem

Long-stay inpatients with disability form a steadily growing cohort in Queensland healthcare facilities. Far from being a situation unique to Queensland, this is a feature of the healthcare system in every state and territory. There are several reasons for this.

- Over the last 50 and more years, advances in medical technology and improved health care have delivered growing numbers of individuals with significant acquired disability and a range of clinical and other needs that are beyond the community support capacity of the existing human services system.
- The development of the human services system as a series of tightly controlled and separate program areas (or silos), such as those that comprise health, disability services, aged care and housing, has resulted in rigid program boundaries. Because of this, programs such as health and disability do not and will not venture outside their prescribed budgetary boundaries or systemic responsibilities. In the case of health and disability services, this means that many clinical supports that people with disability need, even in small measure, are not available outside hospital settings. Outreach clinical services such as behaviour support, nursing and clinical training are simply not delivered. The opportunity to partner with other portfolio areas to deliver the suite of services those with complex health needs require, does not happen, despite the evident need and benefit to all stakeholders in doing so. Without suitable community care arrangements in place, healthcare either looks to aged care or is unable to discharge.
- While disability services are clearly not substitutable for health services, there is a tacit expectation that they are. In deceptively constructing the total needs of a person with disability (including their health needs) as 'disability related', health facility discharge planning immediately looks to disability services to assume responsibility for these individuals at discharge to the community. In many cases, health facility staff have virtually no knowledge of what Disability Services does; that they should involve them in a discharge planning process at all; or even how to begin an application process for a patient preparing for discharge.
- Having evolved historically around the comparatively stable needs of those with congenital disability, disability services does not have the expertise or capacity to deliver clinical supports to effectively – and safely – manage complex health needs. Disability services routinely struggles to deliver safe and competent care for people with PEGs, catheters, tracheostomies and even significant behavioural support needs.
- The chronic underfunding that has characterised disability systems across Australia has resulted in a sustained inability to meet snowballing demand for the most basic of supports; and a systemic resistance to expand their suite of offerings to respond to the presenting needs of otherwise eligible people with complex health needs.

- The aged care sector is now resisting what they see as ‘high risk’ admissions of young people with complex needs where there is no additional funding to augment their support over the long term. There has been a long-standing and naive presumption within health and disability programs that nursing homes can deliver high-level complex care to this group of people exiting hospital care because they have a nursing presence. Over time, aged care providers have taken these people on compassionate grounds but are now alive to the fact that they are simply not resourced to deliver the care that is needed without breaching their standards. Their fee structure gives no recognition to the cost or workforce demands of delivering the complex services required by this group; and the mere presence of nurses in residential facilities is not, of itself, sufficient to deliver care well or safely.

4.2. The current role of the service sectors

4.2.1 Health Services

As providers of acute care, Health Services are often looked to first for help when a crisis develops in an informal (or formal) care situation. Following admittance to hospital via the latter’s emergency department, the individual undergoes the standard round of assessments to arrive at a conclusive diagnosis.¹ Once the hospital is clear that the person’s health has stabilised or is being managed appropriately, it looks to discharge.

The Alliance has worked with many people with multiple conditions that pose challenges for the hospital in how their overall care and discharge planning is managed. Clinical coordination is something that needs to be much better managed by hospitals within the hospital setting for this group.

From the hospital’s point of view, the interface issues for YPINH between hospitals and aged care, and disability and aged care, are often characterised as discharge planning problems. Yet for individuals with complex health needs, such as those with progressive neurological conditions, their management in hospital and delivery of a long-term health management response is often just as critical.

Hospitals commonly manage episodes of care for the YPINH group as single events, meaning that for some people with complex needs, there is a high rate of re-admission due to the incapacity of disability and aged care services to manage the clinical needs of these people. Training and secondary consultancy from the treating hospital is essential as part of good, ongoing care in residential settings for people

¹ As an inpatient, coordination of hospital services and how individuals with complex health needs are treated in acute and sub acute care makes developing a good care plan an imperative. Without good clinical management to comprehensively understand the scope of the person’s issues, the discharge plan (and subsequent care plans) will be deficient.

with complex health needs. However, in our experience, this is rarely – if ever – provided.

If informal care is intact, then discharge to those providing that informal care will occur. It's when informal care has broken down and is no longer available that the problem begins. In the absence of informal care and because the individual is seen to now have 'a disability', the hospital looks to discharge to the Disability Services system or the Aged Care system if the former cannot assist.

4.2.2. Disability Services

Evolving historically to respond to the needs of those with more static congenital disability, the Disability Services system exists in a state of chronic underfunding. In undertaking their responsibility for delivering disability services, all states take a demand management approach to requests for assistance and maintain service needs registers to record those requiring assistance.

Disability Services' offerings of attendant care, residential group homes, equipment and integration into the community for individuals with disability creates a shortfall for those who have clinical and other health needs, needs that Disability Services has neither expertise nor capacity to address. As a result, Disability Services funding and service delivery environment continues to struggle to meet the requirements of those with complex and changing needs.

Attendant care clearly cannot substitute for skilled health and allied health services. Trying to manage complex health and other support needs with more attendant care is unwarranted and completely ineffective. Doing so not only wastes Disability Service's scarce resources but generally results in escalation of the individual's needs to crisis, at which point the individual is (again) sent to hospital.

Disability Services' funding limitations and its design of funding rules means that those with complex needs – such as those with progressive neurological conditions or acquired brain injuries – continue to struggle to obtain increasing levels of service in a timely manner.

4.2.3 Aged care services

Resourced for a very different cohort of frail older Australians approaching the end stages of life, aged care services are ill prepared to manage the different and dynamic health and other supports needed by YPINH.

Yet the lack of community options and the concomitant paucity of infrastructure funding to develop new community service responses, means that aged care will remain one of the "options on the spectrum" for the high and complex health needs cohort for some time to come.

Indeed, the stark reality is that aged care has become the default option for Health and Disability Service programs when their service options either lack the capacity to assist further; or lack the expertise (and capacity) to deliver the care required.

Yet Aged Care's lower staffing levels and lack of appropriate resourcing means that aged care providers also struggle to meet the very different needs of their younger residents. Despite this – despite a dearth of adequate funding to support these younger residents; despite their resultant inability to provide the health and other supports they require – aged care providers do their very best to accommodate the needs of their younger residents when they are asked to assist.

In the case of those with high and complex health needs, residential aged care services are too often required to take a younger resident on discharge from acute care without the training and needed resources (such as equipment, specialist consultancy, care planning, case management and intensity of supervision and personal care), required to manage them appropriately. The result is often the start of a revolving door of hospital admissions involving discharge from acute care to aged care to acute care again to aged care once more and so on, none of which provides an enduring solution but consumes significant health and aged care resources in the process and as it fails.

For the younger person unable to access the supports and services they require, this is a disastrous and distressing state of affairs. It is an equally distressing state of affairs for the aged care provider who may eventually come to realise that, because they cannot successfully manage the complexity of need of their younger residents, they must relinquish care to another service entity, whether a hospital, a locked ward or an inpatient psychiatric service.

For the acute care service, it is a disaster. Already struggling with inadequate funding, sky rocketing demand for health services and the escalating cost of providing health care, hospitals are now increasingly facing provision of long-term accommodation to growing numbers of young people they are unable to discharge to other services. The cost of this drain on health resources is massive – and unnecessary.

4.3. Changing role of the aged care sector

Most individuals with complex health needs enter hospital because of catastrophic injuries; accidents; disease progression/exacerbation; or because informal care in the community has broken down and there is an emergency need for placement. Once a person's health has been stabilised and the acute system can do no more, the process of discharge from hospital begins. At this point – and if the individual is

under 65 years of age – the disability system is called on to provide a response that can include community based disability supports and accommodation.

Historically, and as this submission has already indicated, this group of people have rarely been able to be serviced within the disability system because of its inability to provide clinical supports and/or because of a lack of appropriate and available accommodation options. Prior to the 2006-11 Younger People In Residential Aged Care (YPIRAC) initiative, the common discharge path from hospital for younger people with high and complex health needs was to residential aged care (RAC). YPIRAC offered an opportunity to consider how YPINH might be supported differently.

While YPIRAC had its successes in that a small proportion of the YPINH group were provided with alternative accommodation through the program, some were supported to stay at home and others were provided with ‘top-up’ funding in residential aged care to enhance their quality of life, the program also had some unintended consequences.

One of the most significant of these, and one that directly contributes to the problem of younger people with disability becoming long-stay patients in hospital, is that in the absence of adequate funding to support younger people with complex needs, residential aged care providers came to fully understand the risks and costs they bear when compared to the costs involved in supporting their older residents.

Aged care funding is determined according to a scale outlined in the Commonwealth’s Aged Care Funding Instrument (ACFI).² The ACFI has been calculated to support the needs of frail older residents in the end stages of life, not the more intensive and varied needs of younger people. As a result, RAC providers who take younger people face a substantial funding gap.³

This means that services must either be taken from the older people who form the RAC provider’s target client group; or the younger person in RAC is denied vital supports and services because the provider lacks the funding to deliver them.

While discrete YPIRAC funding provided to younger residents in aged care between 2006-11 remains recurrent, the program was closed to new people from 1 July 2011. This means that there is now no dedicated funding stream through disability services

² For further information on the ACFI and funding scales for residential aged care, see <http://www.health.gov.au/acfi>

³ See the YPINH National Alliance’s submission to the Department of Health and Ageing’s *Review of the Aged Care Funding Instrument*, March 2010. Available online at http://www.ypinh.org.au/images/stories/pdf/acfi_review_submission_mar2010.pdf

for younger people sitting in hospital needing additional funding to enable discharge to RAC, to go home or to move to a community service.

With this growing awareness of the financial, compliance and other risks they face in taking a younger person, aged care providers have started to either refuse hospital discharge requests outright; or demand additional funding from health and/or disability services to augment their efforts. The Alliance is aware of many instances in which the RAC provider has stipulated that appropriate funding and a signed contract to ensure continuity of that funding is required before the provider will consider accepting a younger person into their care.

One of the results of this hardening of response is that growing numbers of younger people with complex health needs are unable to be discharged from hospital and other healthcare facilities to residential aged care. This fact, in concert with disability services lack of resources and expertise to take these younger people, has resulted in the health system increasingly providing long-term accommodation services to this group at enormous cost.

As well as younger people unable to be discharged from acute care hospital services in Queensland, other Queensland Health services such as Casuarina Lodge in Wynnum and Jacana in Bracken Ridge (both notionally Acquired Brain Injury (ABI) rehabilitation centres) have also been forced to act as permanent step-down facilities and provide long term accommodation to people who should have been moved to community settings long ago. As there is no funding for this through disability services, there is a significant blockage at every point in the Queensland system.

Unfortunately, the rehabilitation these services are supposed to offer – services desperately needed but chronically under resourced and undersupplied in Queensland – has diminished over time and is now rarely provided. The individuals with substantial disability who have remained in these settings have become institutionalised and have experienced significant deterioration in their health and well being as a result.

The Alliance expects that when the National Disability Insurance Scheme (DisabilityCare Australia) achieves full scheme towards the end of the decade, it will at least provide some funding capacity for this group. The missing part of the picture remains that there is no cross-sector pathway in place to fund the other clinical supports needed. Because this will not be a role the NDIS will fulfil, there is still no clear way to meet people's health needs across their life course.⁴

⁴ See "Tier 3 – Individually Tailored Supports", *Disability Care and Support*, Report No 54, Vol 1, Section 3.5, Productivity Commission, Canberra, 2011: 165-177.

5. Support needs cannot be met in long-stay healthcare facilities

Remaining in acute care settings over the long term is clearly detrimental to the health and well being of individuals with disability. Quite apart from the chronic institutionalisation that people experience in long inpatient stays, there is an ever-present risk of acquiring antibiotic resistant infections in hospitals such as MRSA, VRE and MDR-TB⁵.

Pressure care is a concern for those confined to bed or with limited opportunity to become more actively engaged; and social isolation, depression and other adverse mental health issues are common. Healthcare facilities do not provide the customised equipment many people require and disabled individuals with stable health often become a lower priority for hospital nursing staff managing the more dynamic and intense health needs of “sick” patients.

The net result is that long term placement in healthcare facilities can lead to loss of important life skills, including continence and mobility skills, that have often been regained during hospital based rehabilitation. The loss of these skills not only increases future care costs, but can limit community service discharge options and lead to further time in acute care.

The Alliance has supported many young Queenslanders and is presently working with several long-stay residents of Queensland Health services. One of these young people has been a resident in a Queensland Health ABI rehabilitation service for over 10 years and in that time, has been continually overlooked for relocation to community based support and accommodation services. His example demonstrates the loss of capacity that is common in long-stay inpatients.

When this young man entered the service on discharge from acute care, he had made a good recovery from a car accident that had left him with an ABI but intact cognition. He was able to walk with assistance as well as independently transfer from his wheelchair and was well on his way to regaining the capacity to speak. Over the subsequent 10 years he has resided at the service and failed to get the supports he needed to maintain and continue his recovery, he has lost the mobility skills he had regained as well as the capacity to communicate.

He now lives in constant and intense pain because of contracture deformities he did not have when he entered the service and has had to have tendon releases in both feet and one hand to try to ease this pain. He has refused to have a tendon release

⁵ Methicillin-Resistant Staphylococcus Aureus (MRSA), Vancomycin-Resistant Enterococcus (VRE) and Multi-Drug-Resistant Mycobacterium Tuberculosis (MDR-TB) are serious health public problems. The risk of exposure to these drug resistant bacteria is magnified by extended periods in hospital. See Gould, C., Rothenberg R. and Steinberg, J. “Antibiotic resistance in long term acute care hospitals: the perfect storm”, *Infection Control and Hospital Epidemiology*, Issue 9, Vol 27, Chicago 2006: 920-925.

in his remaining hand, as this would deny him the capacity to drive his electric wheelchair, the only semblance of independence he has left. The tendon releases in his ankles mean he will never be able to walk independently. He now requires permanent 24-hour support.

Living in this service without the supports he needs, isolated, in constant pain and unable to access the community, has left this young man with severe depression. He has attempted suicide once and continues to ask for assistance to end his life. Despite being recently listed on Disability Services Queensland's (DSQ) Register Of Need (RON), DSQ has indicated they have no capacity to provide a response at this time or in the immediate future.

5.1. Step-down facilities

When discussing solutions to the problem of long-stay patients in hospital, it is sometimes assumed that step-down facilities that are able to meet the personal care needs of individuals on discharge from acute care, provide an answer. Step-down services aim to be less clinical than a hospital, provide 24-hour care with some rehabilitation capacity and, as transitional offerings, be a cheaper alternative to a continuing presence in acute care.

However, the experience of step-down facilities provided through the health system for younger people with disability is generally not positive. Disability services lack of appropriate service development in the community means that transition out of these facilities is slow to non-existent; and while use of step-down services can release acute hospital beds in the short term, their use can also result in highly institutionalised settings that isolate people from their communities.

Rehabilitation services are often not available in the ways that people expect or need in these services; and very low turnover due to the lack of disability services capacity, means step-down services commonly end up with a static population of individuals unable to move home with support or relocate to any alternative accommodation. Unfortunately, and as the all too common scenario described in section 5 of this submission indicates, step-down facilities are too often used to simply move acute care's 'blockage' downstream.

The downstream blockages that step-down services become, mean that within a short time, the pressure once again begins to build in acute care hospitals as the next wave of individuals with disability has nowhere to go. In a number of States where step-down facilities exist, their location in the health system means they do not have adequate links to communities or to contemporary rights-based human services practice. The Alliance is aware of routine neglect of residents in these facilities that is of significant concern.

While there is some merit in the development of specialist services as a ‘gap filler’ for some groups whose needs cannot be adequately met in the general human services system, the Alliance strongly believes that the coordinated approach that joins up service systems in concert with planned community service development, is a precondition for such services to be effective. Unless step-down facilities are developed in this wider context, we would not recommend they be adopted as part of a strategic solution.

6. Rehabilitation

Rehabilitation is an essential service response to aid recovery from injury and exacerbation of disease for the YPINH cohort. Yet outside the compensable system, rehabilitation services do not exist in the quantity or type needed to satisfy this growth in demand in Queensland and nationally.

A lack of rehabilitation and consequent increase in dependency is one of the key reasons young Australians continue to remain in healthcare facilities and continue to enter nursing homes.

In this regard, the Senate’s 2005 Inquiry into Aged Care that had YPINH as one of its terms of reference, noted that “The importance of rehabilitation is not limited to those with acquired brain injury. Those suffering from degenerative diseases also require therapy.”⁶

The Inquiry’s Report further indicated, “...rehabilitation services for people leaving hospital need to be expanded...”⁷ as an essential part of the transition process to home or other community based services. Recommendation 26 reiterated this conclusion by calling on “...the Commonwealth and the States and Territories [to] work cooperatively to reach agreement on...mechanisms, including a funding formula, to provide rehabilitation and other disability-specific health and support services, including specialised equipment...”⁸ to young people with disability needing this assistance.

This view was repeated in the *Younger People In Residential Aged Care (YPIRAC) Mid Term Review* which concluded that supporting those with complex needs “...requires harnessing the interface between health, rehabilitation and disability support services...[and] identified this as a key challenge...” for future programs.⁹

⁶ Senate Community Affairs References Committee, *Quality and Equity in Aged Care*, Canberra 2005. Section 4.66: 98.

⁷ Op. Cit: 7.41: 179

⁸ Op. Cit: 4.173: *xix*.

⁹ FaHCSIA, *Mid Term Review, Younger People in Residential Aged Care (YPIRAC) Program*, Canberra, June 2009: 43.

The Mid Term Review Report further noted that people with complex needs and their families should be placed “...inside of and with clear access to the health and rehabilitation systems and specialist frameworks that have been designed to promote recovery for this population”¹⁰; and that the need for increased program focus in this area had been identified by some jurisdictions.¹¹

Rehabilitation is needed to enhance recovery and independence across the life course. Some of this may need to be an inpatient service but mostly it needs to be delivered where the person is. Victoria’s *Slow To Recover Acquired Brain Injury* program (STR) does this by delivering rehab where the person lives, whether that is at home, in a community supported accommodation service or a nursing home. This non-facility based approach uses skilled allied health input and oversight to develop a rehab program that is carried out by disability support workers trained by the allied health specialists. This cost effective approach has delivered significant benefit to the individuals on the program.

Delivery of rehabilitation services must be considered as part of the integrated service response those with complex health needs require.

7. Disability and healthcare working together

One of the central issues for any individual with complex health needs is that our health system does not accept responsibility for ongoing management and oversight of complex health needs outside healthcare facilities. Instead, the health system seeks to discharge to other areas of the service system, regardless of the existence or otherwise of the resources or the expertise to effectively manage the needs of these individuals.

One of the realities of the YPIRAC initiative was that disability providers were given responsibility for managing the complex health needs of young people moving out of nursing homes. Asked to do no more than deliver standard disability service responses, service providers used higher levels of attendant care to meet the health needs of residents.

As indicated earlier in this submission, disability services cannot substitute for skilled health and allied health services. Trying to manage complex health and other support needs with more attendant care can be ineffective and often dangerous; and without the comprehensive planning, targeted services and expert coordination required, can result in mismanaging the individual’s needs to a degree that risks crisis and recurrent hospitalisation.

¹⁰ Ibid.

¹¹ Ibid.

The Alliance is aware of too many instances in which this lack of clinical expertise and worker training in the health needs of YPIRAC participants has resulted in the steady deterioration in health and well being of these individuals in newly developed disability services. In a small number of cases, individuals have died because the clinical care they need has not been available. In other cases, people have been hospitalised and been unable to return to their residence because the disability service provider has refused to take them back without additional clinical input and support.

What this points to is the urgent need for a better connection between health and disability services to ensure people do not risk repeat episodes of hospitalisation and long inpatient stays and can maintain their health and well being over the long term.

Working with the Alliance, one Victorian health network has already developed and implemented a coordinated discharge approach that brings hospital staff and state disability services representatives together to work collaboratively on discharge planning for individuals exiting hospital (see Appendix B, page 36 of this submission). If disability services are unable to offer a community accommodation option, an aged care provider is invited to participate in the discharge process.

As part of discharge and transition arrangements, the hospital works with the disability or aged care provider to educate and train their staff in the patient's needs. If needed, transition funding is provided by the hospital to 'bulk up' the providers' capacities so that those first critically important days and weeks immediately post discharge, are proactively supported. At discharge, the hospital 'follows their patient into the community' and works alongside the provider, overseeing the transition process and providing reassurance and support to providers and their staff.

In the absence of a viable disability supported accommodation placement, aged care placement is never considered a permanent alternative but is always agreed to as a transition-to-the-community option. The individual's request for a community supported accommodation service retains an 'active' designation on disability service's service needs register; and disability services contributes funding – when it has funding available – to enable community access and other disability services the aged care provider is not resourced for, to be delivered in the nursing home.

This process has provided a safer and more successful transition to the community for individuals with a disability than would otherwise have been possible. Because providers are actively supported and the hospital is willing to provide funding to support the process itself, hospital readmissions and long-stay inpatient numbers have been reduced. The process has also given health, disability and aged care service providers the opportunity to better know and understand the processes, procedures and constraints that other program areas confront and from this, work

collaboratively to deliver the best discharge response possible for the individual to the mutual benefit of all involved.

This is a rare but highly effective model that could be replicated in other health systems. The Alliance is happy to provide further details of this innovative approach if required.

8. Advent of DisabilityCare Australia (DCA)

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 interrogate and involve Health and Aged Care services as well as Disability Services in determining service responses for launch site clients, remains to be seen. At the very least, DCA should, as a matter of urgency, take steps to establish collaborative partnerships with health, aged care, housing and other program sectors that form part of a life course response.

Doing so will not only benefit the individuals who need a skilled, integrated response. It will also deliver clear cost benefits to health, aged care and disability services as well as to the scheme itself; and potentially lead to development of a new suite of service responses for individuals with this level of complex health and other needs.

The interim before DisabilityCare Australia 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 DCA will need for its clients with complex needs in the future.

8.1. DisabilityCare Australia in Queensland

While the Queensland Government's sign-up to DisabilityCare Australia has delivered high expectation that DCA will resolve many longstanding areas of need for Queenslanders with disability, this national scheme will have capacity to tackle only part of this problem.

DCA will deliver an improved supply of disability support services such as attendant care, customised equipment, community access and the like. But it has extremely limited capacity to tackle the widespread lack of accommodation options that forms part of this problem; and will need to work closely with health services to develop the community health responses that individuals with complex health needs will require.

While the scheme has only just started with limited rollout in other states, it is not projected to begin in Queensland until 1 July 2016. An implementation plan will not be in place before end December 2014, with a progressive rollout aiming to ‘cover’ all Queenslanders with a disability by 1 July 2019.¹²

This extended timeline and the delay in the scheme reaching all Queenslanders means those with disability and complex health needs will continue to be without the joined up supports they require in the interim. Indeed, there is no present indication of efforts to work with the health system to manage the complex health needs scheme participants may present with; or develop a skilled workforce able to deliver this support in community settings.

Most disturbingly perhaps, the Alliance has anecdotal evidence that the Queensland Government is already actively reducing vital disability services – including crucially needed Intensive Behaviour Support teams – in anticipation of the arrival of DCA. Again, this activity is not unique to Queensland. The Alliance is aware of other states undertaking similar cost cutting and cost shifts to support delivery of their agreed funding contribution to the national scheme.

However, if funding continues to be “withdrawn” and general disability services’ capacities continue to be reduced to enable the states to deliver on their DCA funding commitments, the situation becomes even more dire for those outside the launch sites who must wait for the scheme to achieve full rollout to get any assistance from it at all.

While DCA will undoubtedly do a great deal to deliver improved lives to many Queenslanders with disability, there is no indication at present as to how it will manage the complex health needs group in community settings; what models of care it will generate or purchase; and how it will interface with State and Territory Health portfolios. Finally, its delayed start date with full rollout by 2019 in Queensland, means that the enduring issue of individuals with disability remaining in healthcare facilities is set to continue. Given that DCA will not provide an overnight solution, there is no room for complacency in any part of the system concerned with resolving these issues over the short, medium or longer term.

¹² See the Queensland Government’s Department of Communities, Child Safety and Disability Services online information portal at <http://www.communities.qld.gov.au/disability/key-projects/disabilitycare-australia-the-national-disability-insurance-scheme>. The Heads of Agreement between the Queensland and Commonwealth Governments that details the Scheme’s reach and responsibility is available at <http://www.communities.qld.gov.au/resources/disability/key-projects/national-disability-insurance-scheme/heads-of-agreement-signed-8-may-2013.pdf> Accessed online, 14 August 2013.

9. Where are needs best met

Individuals with complex health and other support requirements commonly need to access multiple services from a range of program areas simultaneously, and want to do so in their own communities, not in institutional settings. Yet the service system's current configuration and preference for keeping services within designated program boundaries does not enable such an integrated or 'joined up' service response at either the community or facility level.

The Alliance believes that partnership and collaboration between health and disability programs particularly, but also housing and sometimes aged care, can deliver the multi-program, integrated service responses that are needed. To deliver this, a proactive lifetime support model of care that centres on collaboration and commitment of relevant expertise by the different programs involved; and uses a hybrid of care coordination, risk management, advocacy and information provision to develop and deliver an integrated service response, is needed.

Doing so not only benefits the individuals who need this skilled 'joined up' response. It can 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.

However, to implement any form of joined up response, skilled coordination is required. Our experience with the Continuous Care Pilots (CCP) in Victoria and New South Wales and our own work in Queensland indicates that the role needs to be well defined, well mandated and undertaken by highly competent people.

While this role was specifically created for the CCPs, it does not presently exist in the disability, aged care or health systems. For the collaborative approach to work in the Queensland context, we would recommend that specialist roles be funded by DSQ and located in community agencies. These roles would be responsible for the planning and implementation ('directing traffic') of individual programs that are jointly funded by health, disability and aged care. Each program would contribute funds and key personnel required for program implementation.

10. Solutions

10.1. Integrated or joined up service responses

The problem of individuals with disability remaining in health care facilities over the long term is not an intractable one to solve. What is needed to address it is a commitment to individual outcomes through a collaborative mechanism that involves health services, disability services, housing and aged care. 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.¹³

The common sense alternative of embracing an integrated approach is actually possible. 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 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 or clinical management can be drawn from different areas appropriately.

Facilitating a move away from the fragmented scenario currently in place will need leadership from the top of the State Government. It will need a mandate from the Premier and his stewardship to make hard wired ministers and departments change their ways.

In some ways, the coordination of services across departments has been a holy grail. But with the significant pressures on State Health systems that the ageing of the population and shrinking relative budgets have delivered, there is now a real incentive to get Health to the table to design and deliver a sustainable solution.

Without this action, the reality remains that the hospital system in Queensland is effectively underwriting the failure of the disability system and doing so at a much higher cost than disability would be paying to accommodate or support these long-stay patients in the community.

Because funding for hospital beds or hospital services is not portable, it is not feasible to advocate for a shift in resourcing to come from hospitals to support community accommodation. Yet, part of the solution to this problem of long-stay

¹³ See the Continuous Care Pilots undertaken in Victoria and NSW as part of the Younger People In Residential Aged Care (YPIRAC) initiative. These 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>

patients does lie in making the expertise and capacity of the hospital system more portable.

The health system needs to be proactive in addressing this problem rather than doing nothing. An effective defensive strategy needs to be adopted by Health to manage the risks of long-stay patients, as no other sector – and Disability Services especially – is going to solve the problem for them. But it can be done if incentives are identified and pursued for both portfolios.

Such a strategy needs to include individualised funding for clinical services as well as training/secondary consultancy and collaborative planning with the other sectors. One way of doing this is to create a flexible pool of funds that sits in the health system that can be drawn on to tailor packages of clinical supports to individuals who are long-stay patients (or at risk of becoming one) to complement other programs such as disability services or aged care.

A demonstration of this kind of approach was provided by the Department of Health and Ageing in 2005 with the Innovative Pool Aged Care/Disability interface program. In this program, flexible aged care packages were made available to disability providers to supplement their service to provide clinical care for individuals identified as being at risk of premature admission to RAC. The program was thoroughly evaluated by the AIHW¹⁴ and found to be highly successful, but was time limited. Subsequent bureaucratic changes to the way the States and Territories and the Commonwealth fund disability and Aged Care through the Home And Community Care (HACC) Agreement, meant that there was no longer any capacity for joint funding through this program.

10.2. Aged care as transition

It is likely that residential aged care (RAC) will continue to play an important role for those with complex health and other needs, long into the future. However, with the right coordinated approach, RAC need no longer be a premature and permanent destination for those with complex needs simply because no other options are available. It can provide important transitional support services as an interim response.

Delivering a transitional service would enable rehabilitation and other sub acute service delivery (if available) to 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

¹⁴ Australian Institute of Health and Welfare, 2006, National evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot, Final report, Aged Care series no 12, Canberra. For further information see <http://www.aihw.gov.au/aged-care-innovative-pool-evaluation/>

the supports, accommodation and resources needed to enable the younger person to return to life in the community in a safe and supported manner.

In a joined up approach, aged care could have porous boundaries, with other programs complementing its base service provision with developmental and specialist services. A clear exit point would be agreed by all partners before entry to RAC; and ongoing monitoring and review would be in place also to manage changing health and other needs over the transition period, as well as ensuring exit to the community is achieved in the agreed timeframe.

In addition, disability and health funding and program partnership would accompany the YPINH into RAC to deliver rehabilitation services, personal support (to augment RAC's contribution and ensure the younger person's more intense needs can be properly supported), aids and equipment (including high end pressure care) and community access.

Partnering with RAC to deliver a transition option can deliver considerable benefits to all partners:

- Health gains through coordinated provision of rehabilitation services and inclusion of disability partnered funding and care that reduces the likelihood of recurrent admissions to acute care.
- Aged care gains through
 - Collaborative funding from disability that 'tops up' provision of personal support, program collaboration and contribution to aids and equipment and community access;
 - Health's contribution around rehabilitation and allied health supports that alleviates the intense pressure on limited RAC resources; stops the diversion of these resources away from their aged care clientele; and ensures staff can devote proper attention to their aged clients.
- Disability gains because partnering with RAC in this way provides a 'breathing space' in which coordinated service responses can be developed and community support and accommodation service options can be organised and delivered. In addition, because the individual's health and well-being has been maintained at optimal levels, transition to the community can proceed smoothly and with minimal fuss.

Under a joined up approach, there will be 'options on the spectrum' to enable individuals with complex health and other needs and their families to have a choice about where they live after they transition out of RAC and how they are supported. Rather than expecting a young person to accommodate the setting, whether it suits their needs or not, the development of individually targeted accommodation and support responses enables the delivery of lives of meaning and dignity in both the short and the long term.

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11. Conclusion

Rather than the current practices of episodic care, married with 'set and forget' planning in a landscape of programmatic cost shifting, the Alliance believes that a lifetime support approach is the most effective paradigm for those with complex health and other support needs. Such an approach can deliver the integrated service responses that are essential to maintain the health and well being of the YPINH group and others in long-stay healthcare facilities over the long term.

While undertaking such an approach may require some 'wiring changes' to some of the portfolio areas involved, there are certainly clear financial and social imperatives to do so, particularly for health.

The problem of long-stay patients in healthcare facilities can only be addressed comprehensively if all program areas accept that they are, in fact, contributors to the lifetime support of these individuals.

Doing so means a different, more effective outcome becomes possible, one that will deliver mutual benefit to all stakeholders and may even offer the same improved outcomes to others in the community who need an integrated response to meet their needs.

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Appendix A. Case Studies

Case Study 1: Sienna

Sienna is a 30-year-old woman diagnosed with Young Onset Dementia (YOD). 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 services and minimal home services for Sienna's parents.

Their advancing age, the deterioration of her physical, emotional and mental state as well as the development of challenging behaviours in their daughter that they have been increasingly unable to manage, meant Sienna's parents reached the distressing conclusion that they could no longer adequately support their daughter themselves. As a result, they began 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 high care 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 combined with her progressive disability 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 these 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.

Over the four weeks she spent in hospital, doctors and other staff 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.¹⁵ But despite this, the unfamiliar surrounds and constant changes in routine left Sienna ever more distressed, a distress expressed through ever greater escalation of aggressive behaviours to the point where Sienna was at times physically restrained by hospital security staff.

Once Sienna’s health had stabilised, however, and the hospital felt it could do no more, it was keen to discharge Sienna to the nursing home without delay. Following her first brief stay, the nursing home was this time acutely 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, to provide a highly individualised support program. Because this additional funding could not be made available from either source, 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.

Having been involved with the family in trying to get the community accommodation and supports Sienna needed, the Alliance took on the role of key coordinating agent with the hospital, disability services 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.

¹⁵ 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.

In efforts to get a workable outcome, 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 related services.

Disability Services was similarly reluctant to engage. The common response was that as Sienna would technically be 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 something that was seen to be relevant. While Disability Services staff were personally concerned about Sienna's interests, they could do little to influence their systemic response.

For the hospital (and by extension the Health Department), this enduring stalemate was finally broken when they realised that

- The nursing home would not accept Sienna again without funding and other supports from both Health and Disability Services and there was a clear and present reality that Sienna may well become a long-stay patient;
- Sienna was highly likely to re-present at emergency if the move to aged care did occur but failed again;
- The nursing home was likely to refuse to accept Sienna on discharge from any subsequent hospital re-admission, almost guaranteeing that the hospital would have 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 to top up Commonwealth aged care funding would, in fact be cheaper than Disability Services taking 100% of the responsibility for Sienna's care long term, particularly given there were few realistic options for accommodation at that time.

Transition funding, expertise and services were finally committed by both Health and Disability Services to support Sienna's discharge to the nursing home. This funding had to be used by the end of the financial year, which was some 2 months away at that time. There was no funding or commitment in place to continue supporting the nursing home's efforts after that.

With active nursing support for the first two days from health services, Sienna was transferred to the nursing home. Transition funding was used to deliver 1:1 care 24/7 for the first 2 weeks and was then used to augment the nursing home's lower

staffing levels after that. The intensive levels of staffing and care involved meant that this funding was quickly used up and the nursing home was left to rely on its aged care resources only.

This left the nursing home trying to accommodate Sienna's intense needs and challenging behaviours via an aged care approach that was never meant to manage this level of care and input.

Despite the aged care provider's very best efforts over three weeks; and the direct involvement of Queensland Health at the nursing home on a number of occasions, this placement eventually failed. Aged care had neither the expertise, the resourcing or the capacity to provide the 24-hour, one-to-one care this young woman requires to stabilise her health and manage her fragile and deteriorating mental and emotional state.

During her time in the nursing home, Sienna's behaviour escalated and resulted in the destruction of all furniture and furnishings in her room and several holes being gouged in the plasterboard walls. It was when Sienna started pulling electrical wiring out of the walls that the nursing home decided there was evident risk to Sienna, to their older residents and to the staff themselves in Sienna remaining in their care. The nursing home had no choice but to call an ambulance and she was returned to the local hospital.

Trying to manage the intensity and dynamic nature of Sienna's needs left the nursing home staff exhausted. By the time she was returned to hospital, several staff had refused to continue working with her and three were on extended sick leave as a result of their efforts with Sienna.

At the time of this submission, Sienna has remained in the hospital for 10 weeks in a special dementia ward while doctors attempt to develop a specialised management plan for her. Hospital staff now believe they have done as much as they can and are looking to discharge Sienna once more.

The Alliance recently attended a case conference meeting held at the hospital with members of the hospital's medical, nursing and allied health staff, as well as several representatives from DSQ and Sienna's family.

The lengthy discussion that occurred centred on the type and availability of community options suitable for this young woman to be discharged to; the need for substantial transition planning to achieve a successful discharge; the ongoing need for outreach services from health to support Sienna's health needs in the community post discharge; and the need for a team of support workers to be fully and comprehensively trained in Sienna's needs before she is discharged from hospital.

Hospital staff were clear that one-to-one care was needed to manage Sienna's challenging behaviours and to keep Sienna safe. They further indicated that the right mix of staff and their education in Sienna's needs was critical to the success of any placement. The staff also indicated that they were under some pressure to discharge Sienna, now that her condition was considered comparatively 'stable' (in strict health terms).

The hospital's representatives indicated that they believed an accommodation service in the community, shared with one other person and with the funding needed to deliver the intensive levels of support Sienna required, would be the best outcome for her on discharge and over the longer term.

At this point, Disability Services once again indicated that, despite an ongoing desire to assist, it had no capacity to take Sienna on discharge from the hospital due to a lack of accommodation options for her in their system. They also reiterated that they did not possess the clinical expertise needed to manage her dynamic health needs; nor did they have the funding required to provide the intensive support she would need, were she to move to a disability supported accommodation service in the community.

The hospital then indicated that while Sienna required active health involvement to manage her dynamic health needs, it had no capacity to continue providing this level of support or involvement to Sienna post discharge; and that aged care must therefore be looked to as a discharge option.

The Alliance had to remind the meeting that aged care would also require substantial funding input as well as continued health and allied health supports to successfully support Sienna, should a nursing home be found that was willing to take her.

In further discussion, the Alliance reiterated that without continued and proactive health care management of Sienna's needs in the community, discharge to either aged care or disability services was likely to fail and Sienna would re-present at the hospital's emergency department within a matter of days post discharge.

At this point, the Alliance facilitated an open discussion of options available in the health system that could be called on to deliver this vital health input and it was decided that the following could be made available through the health service:

- A local GP, fully educated in Sienna's treatment regime to manage her needs in the community and with direct access to those hospital specialists who had devised Sienna's management plan, would be sourced
- A dedicated nurse practitioner already based at the hospital, would be available to support staff in the community service in management of Sienna's needs and

- Access to the hospital's cognitive disorders unit would also be available for ongoing assistance and support.

Had the Alliance not taken the lead coordinating role it did, it is highly unlikely that this health outreach plan would have been conceived. There was no other service representative or official in the meeting who had the mandate to go beyond their own program or budget, something that limited the ability of those present to lead a solution-focused planning process.

DSQ again reiterated that disability resourcing was in extremely short supply with services being closed as part of preparation for the arrival of DisabilityCare Australia; that new recurrent funding was practically non-existent; and that access to additional funding was likely to occur only when someone in receipt of DSQ's funding moved interstate or died.

Final outcomes included that the hospital would investigate aged care options; that DSQ would refer Sienna's case and request for significant additional funding to its Regional Director for review; and that, following its first letter to the Queensland Premier asking for his intervention to broker the cross program response Sienna needed, the Alliance would write again to the Queensland Premier to provide an update on the meeting's outcomes.

At the time of writing, we are aware that the letter has been actioned but are still waiting on a response from the Premier.

Case Study 2: James

A 32-year-old man with an Acquired Brain Injury and multiple chronic health needs, James has been a resident in a Queensland ABI rehabilitation 'step-down' service for over 10 years.

James was 21 years old when he lost control of his ute on a country road in Queensland and crashed.¹⁶ Despite the extensive injuries he received, James did not receive a head injury from the accident. He was taken to hospital conscious and talking and with an excellent chance of recovering completely.

¹⁶ The accident was the result of another driver losing control on a bend, James swerving to avoid the oncoming car and subsequently losing control of his car and crashing. Because of the hypoxic brain injury James suffered in hospital and the loss of memory his brain injury left him with, James was unable to recall the sequence of events leading to the accident until well over a year later. By then, he was outside the timeframe that Queensland's fault based motor vehicle scheme applies for notification of an accident by one month. Despite the driver of the other car being identified and admitting culpability – an admission that made James eligible for its support – James has never received any assistance from the Queensland Motor Accident Commission.

However, the trauma his body had endured resulted in a massive heart attack in the hospital's emergency department. Delays in reviving him in hospital left James with a hypoxic brain injury.

James received 'fast track' rehabilitation while he was an inpatient in hospital, making significant gains and demonstrating excellent capacity to regain his capacities further. Once his health was stable, James was discharged to one of Queensland's step-down ABI rehabilitation services.

When James entered the ABI service, his cognition was intact and he was able to walk with assistance as well as independently transfer from his wheelchair and was well on his way to regaining the capacity to speak. He looked forward to recovering further and getting on with his life. For a short time, he received enhanced allied health supports in the step-down service to maintain the recovery he had made.

But the service's chronic under-resourcing; the rapidly revolving door of allied health and clinical staff that constantly moved through the service; and the human services system's failure to discharge James to a community service, led to a gradual withdrawal of the crucial allied health supports James needed to maintain his capacities and recover further.

Despite his parents' constant requests for information and resumption of the supports their son needed, James received fewer and fewer allied health supports as time passed. Eventually the trickle he had been getting stopped entirely, the promise of fortnightly hydrotherapy never eventuating.

His hydrotherapy provided James with his only avenue of pain relief. But recent cuts in health funding, uncertainty about the ABI service's future and its subsequent transition to a mental health rehabilitation service, have left James with an offer of a heated wheat bag only to manage the intense pain he lives with and that only when (and if) a staff member is available to provide one.

James is put to bed at 4pm each afternoon and remains there until staff come to get him up the next morning. He is unable to move independently during the night and, despite needing 2 hourly turns throughout the night to avoid pressure problems, is left in one position until staff come to get him out of bed the next morning at 6am.

At this point and because he has been left in one position for nearly 14 hours, James is given Valium in an attempt to manage the severe pain, stiffness and headaches he has every morning due to the lack of overnight care.

Over the more than 10 years he has resided at the service and failed to get the supports he needed to maintain and continue his recovery, James has lost the mobility skills he had regained after his accident, as well as his capacity to communicate. He can no longer walk or transfer independently and requires 24/7

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support. Because his speech therapy was discontinued, James' efforts to regain the capacity to speak stalled and have regressed. As a young man with intact cognition, his inability to speak is one of the greatest frustrations he lives with.

James now lives in constant and intense pain because of contracture deformities he did not have when he entered the service and has had to have tendon releases in both feet and one hand to try to ease this pain. He has refused to have a tendon release in his remaining hand, as this would deny him the capacity to drive his electric wheelchair, the only semblance of independence he has left. The tendon releases in his ankles mean he will never be able to walk independently again.

Living in this service without the supports he needs, isolated, in constant pain and unable to access the community, has left this young man with severe depression. He has attempted suicide once and continues to ask for assistance to end his life.

Despite being recently listed on Disability Services Queensland's (DSQ) Register Of Need (RON), DSQ has indicated they have no capacity to provide a response at this time or in the immediate future.

Case study 3: Diana

45-year-old Diana has a rare neurological condition that has left her unable to move the right side of body (hemiparesis) and with limited capacity to communicate. Despite these impairments, Diana has the ability to interact with her environment at a high level of functioning.

A single mother of 4 children, Diana's condition had remained relatively stable until she awoke one morning unable to move or speak. She was taken by ambulance to one of Brisbane's major teaching hospitals and close friends who lived nearby cared for her children.

Over a period of weeks, Diana's health stabilised with a new drug regime. Diana's speech did not return however and despite fast track rehab and allied health input in hospital, her right hemiparesis remained.

Once her health had stabilised, the hospital began attempts to discharge her to disability services. Over the next several months, disability services was unable to offer a viable community option that would deliver the clinical care Diana needed. In the absence of a disability services option, the hospital began looking to placement in a residential aged care service.

However, despite approaching a large number of nursing homes to take Diana, the hospital was unsuccessful. The nursing homes approached were clear that without

substantial funding to augment their care and deliver the specialist supports Diana needed, they would not accept her.

Having decided that Diana's recovery had 'plateaued' and needing to redirect its scarce allied health resources to patients "able to take advantage" of this level of care, the hospital's minimal allied health input to Diana started to be gradually withdrawn, despite Diana needing this input to maintain her existing capacities.

The Alliance was asked to become involved when Diana's interstate based parents wrote to then Prime Minister Kevin Rudd and federal Families, Housing, Community Services and Indigenous Affairs Minister, Jenny Macklin, for assistance. By this point, Diana's parents had employed a specialist consultant to find an appropriate nursing home for her to move to. Like the hospital, the consultant could not find a nursing home willing to take Diana without a guarantee of the substantial funding and other supports the aged care service would need to care for Diana, funding that neither health nor disability services could – or would – provide.

The Alliance worked with DSQ, several Queensland community and member organisations and a not-for-profit aged care provider willing to take Diana as an interim or transition placement on discharge from hospital. With DSQ's agreement and support, Diana was maintained on their Register of Need (RON) as someone currently needing community placement, despite her move to residential aged care.

One of Diana's key needs was to continue parenting her children as much as possible while she lived in the nursing home. Yet DSQ's lack of funding meant it had no capacity to provide the funds needed for Diana to access the community and see her children. Nor did it have capacity to provide the high-end pressure mattress she needed, a hoist to assist with transfers in the nursing home or the other equipment Diana required. It was also unable to provide funds for Diana's allied health assessments; or to augment the nursing home's lower staffing levels to enable it to provide the more intensive levels of care Diana needed.

Over the course of several case conferences with representatives from the community organisations involved, DSQ, the Alliance and the hospital, the latter reiterated that it had no capacity to contribute funding or expertise to a transition arrangement or provide longer-term support to the nursing home. The hospital's key concern remained to achieve discharge as soon as possible.

In the absence of the funding she needed, the Alliance and the community organisations involved jointly contributed the funding needed to allow Diana to access the community and see her children; and to purchase an iPad as a communication aid. The Alliance also organised a trial of a high-end pressure mattress for Diana and when this mattress proved successful, funded the purchase

of a new one for Diana. The hospital made a successful submission for funding for an electric wheelchair through Queensland's Medical Aids Subsidy Scheme (MASS) and Diana moved to the nursing home shortly before Christmas.

Case conferences convened after Diana moved to the nursing home involving the nursing home's Director Of Nursing (DON), DSQ, the Alliance and the community organisations supporting Diana, identified the following concerns. From the nursing home's point of view, there was continual frustration in its efforts to provide adequate and appropriate care to Diana in the absence of the funding and equipment it needed to do so. Staffing levels and a limited number of hoists meant Diana was limited in her access to three showers per week, despite needing a daily shower because of her medical needs. The nursing home remained highly concerned about skin breakdown and pressure issues that might result, despite its efforts to ensure Diana's well being.

The nursing home continued to request funding for a minimum additional 14 support hours per week to provide Diana with a daily complement of one hour of personal support and one hour of assistance with therapy needs, including communication. Without these additional resources, the nursing home management made it clear that Diana's interim placement there was at risk.

Of additional concern was Diana's need to access the drugs she required to manage her disease. Because of its rarity, the drugs Diana needed could only be dispensed by the large public hospital she had been discharged from. A local GP was unable to prescribe and dispense the drugs; and the discharging hospital had no mechanism to dispense and deliver these vital drugs to the nursing home that was over an hour's drive away. Nor did the nursing home have either the capacity or a viable mechanism whereby it could retrieve the drugs from the dispensing hospital.

It was left to one of Diana's friends to undertake to drive to the dispensing hospital, pick up the drugs and deliver them to the nursing home. Diana's drug regime was finely tuned and she could not afford to miss a dose or be late receiving one. This arrangement was therefore precariously balanced, depending on the goodwill and commitment of a friend and a lack of unforeseen events that might prevent the friend retrieving the medication from the dispensing hospital and returning it to the nursing home on time. On more than one occasion and for reasons outside anyone's control, the medication delivery was delayed.

The nursing home continued to advocate for additional funding to buy the allied health supports Diana needed, especially those required to assist with communication. While the nursing home did have a physiotherapist on staff, it was made clear that because of the number of residents, Diana would not receive regular physio sessions.

Regular meetings between the stakeholders supporting Diana kept her need to move to community accommodation 'alive' and front of mind for disability services. The nursing home continued to request additional funding and indicated that as well as a pressure mattress, Diana needed her own shower/commode chair, a hi-lo electric bed, a bar to facilitate movement in bed and an over bed table. The nursing home indicated that it did not have this equipment itself to offer Diana and had no resources to buy it.

One of the community organisations drew on its donations to pay for equipment hire for this essential equipment for Diana while she was living in the nursing home. Neither the equipment nor the funding the nursing home requested to care appropriately for Diana ever became available.

Fortunately for Diana and for the nursing home, a vacancy became available in one of the few high needs services funded by DSQ. After the relevant investigations regarding suitability, the service's capacity to support Diana and staff training had been undertaken, Diana successfully transitioned to the community service after 7-8 months in the nursing home.

Living in a supportive community setting with the clinical and other supports she requires; where she has her own 'place' and a routine that suits her particular needs; a place where Diana's children are encouraged to visit regularly and stay the weekend, has made all the difference to Diana. She continues to make significant gains in her recovery and was recently able to make a phone call to speak to her parents, something that had been considered impossible previously.

Like many others who have tried to assist, the experience of supporting a younger person with complex and intense health and other support needs without the resources to do so, was a bridge too far for the nursing home. They have indicated they are unlikely to consider accepting a younger person into their care again and if they were to be persuaded, would expect the full suite of resources and health supports needed to be in place.

Appendix B
Healthcare and disability services collaboration

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 INSIGHT



Star (Sunshine-Ardeer-Albion), Melbourne
 13 Aug 2013, by Alesha Capone

General News, page 9 - 205.62 cm²
 Suburban - circulation 30,814 (-T-----)

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Patient Kim Nguyen with Rebecca Camilleri and Sue Race from Western Health, who is a finalist in the National Disability Awards. 103530
 Picture: NICOLE SULTANA

Running the good Race

By ALESHA CAPONE

SUE Race and her team at Western Health have helped many young patients find a home outside hospital.

Hard work and dedication have led to Ms Race, a St Albans resident, being named as a finalist in this year's National Disability Awards in the category of Excellence in Improving Health Outcomes.

Ms Race is a divisional director of Sub Acute and Aged Care Services at Western Health, which covers Sunshine Hospital, Western Hospital in Footscray and Williamstown Hospital.

As part of her job at Western

Health, Ms Race has developed a hospital discharge planning process which helps patients with a disability to find a home where their health needs are supported.

This, in turn, helps the patients to avoid long-term hospital stays.

Ms Race said she was "very humbled" to be recognised as a finalist in the awards.

Ms Race and her colleague, nurse unit manager Rebecca Camilleri, said they worked with the Young People in Nursing Homes - National Alliance as part of the discharge process.

Often they find homes for young people whose family members have died or whose

relatives are unable to care for them any longer.

Ms Race said the program involved contacting government departments, services and agencies to find a suitable residence for each patient, then creating an individual transition plan for their first weeks in the new home.

"It is really rewarding when it works out, and especially when they keep in touch, or we hear through the Alliance they are doing well and loving it in their new home," Ms Race said.

"It is a lovely feeling, they are like a family and you want them to go to the best homes possible," Ms Camilleri said.

Submission to the Queensland Office of the Public Advocate's Inquiry into People with Disability in Long-Stay Healthcare Facilities, August 2013.

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