

# Office of the Public Advocate (Qld) Systems Advocacy

## Submission to the Senate Standing Committee on Community Affairs

*Adequacy of existing residential care  
arrangements available for young people with  
severe physical, mental or intellectual  
disabilities in Australia*

**February 2015**

# Foreword by the Public Advocate

## Interest of the Public Advocate

The Public Advocate was established by the *Guardianship and Administration Act 2000* to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

Through our work, we estimate that there may be up to 113,000 people with impaired decision-making capacity in Queensland. Queensland adults with impaired decision-making capacity are among the most disadvantaged people in the community. An unacceptably high level of disadvantage is experienced across a range of social and economic indicators. This disadvantage significantly reduces quality of life and increases the risk of abuse, neglect and exploitation.

## People with disability in health facilities in Queensland – Public Advocate’s Inquiry

Of great concern to me is that while many institutional living environments have now closed and there has been an increase in community-based living arrangements, there are still many people with disability living in institutional type settings who are segregated from the community. Many of these individuals have limited opportunities to increase their autonomy, capability, participation and inclusion. These include both long-stay health care facilities (hospitals, mental health services, ‘rehabilitation services’) and aged care facilities.

In response to these concerns, I distributed a Position Statement (on continuing the deinstitutionalisation of people with disability in Queensland) in June 2013 calling on the Queensland Government to carefully develop a plan, based on thorough consultation, to enable increased autonomy for people with disability living in ‘institutional’ settings while facilitating access to increasingly appropriate support arrangements.

Coinciding with the release of this position statement, I also put out a call for submissions in relation to this issue and sought information from key Queensland Government departments about the number of people who continue to reside in long-stay health care facilities, and the extent to which they are working together to plan for more appropriate community-based accommodation and support services for these individuals.

I also visited a number of health facilities including Baillie Henderson Hospital in Toowoomba; Halwyn Centre at Red Hill; Jacana Acquired Brain Injury Service at Bracken Ridge and Casuarina Rehabilitation Centre and spoke to staff and residents there.

This submission is largely informed by the results of this inquiry in Queensland and the final report—*People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation*, which was tabled in the Queensland Parliament on 7 November 2013.

This submission is divided into two sections:

- A. **People with disability in health care facilities in Queensland – Findings of the Office of the Public Advocate** (detailing the results of the Public Advocate’s inquiry into people with intellectual disability or cognitive impairment residing long-term in health care facilities).
- B. **Options, consequences and considerations for deinstitutionalisation** (outlining the principles that should inform the deinstitutionalisation process).

## Position of the Public Advocate

Queensland is scheduled to commence implementation of the National Disability Insurance Scheme (NDIS) from July 2016. Yet significant numbers of people with severe physical, mental and intellectual disabilities continue to reside in psychiatric hospitals, other long-stay health care facilities and aged care facilities.

This is unacceptable and not at all consistent with contemporary standards in respect of the provision of supports and services to people with disability.

It is neither acceptable nor appropriate for people with disabilities to continue living in hospitals and other institutional environments. Many people in these environments have little access to the community; others have none at all. Nor are people provided with educational or vocational opportunities. This lack of opportunity to access the community and to learn and develop is unfair, and results in a severely inequitable situation that directly contravenes Australia's human rights obligations and fails to meet contemporary models of support and moral standards.

Furthermore, in many cases it does not make good economic sense to care for people in acute hospital beds, for example, when the same person could be receiving more appropriate support in a community-based setting at a significantly reduced cost.

When touring various health facilities and meeting with residents as part of my inquiry in 2013, I was struck by the inequity of their situation. Many people with similar levels of disability live happy and fulfilled lives in the community, yet this group of people have 'missed out'. They were in the wrong place at the wrong time. This is not only unfair to them, but also to their families.

The current approach is wasteful and bureaucratic and has real costs, both for the people who live in these facilities and economically for Government. The model of care provided in these facilities (where people with disability are segregated from the community) also reflects an outdated perspective of disability.

As Queensland and other states and territories 'ready' themselves for the transition to the NDIS, consideration for the needs of individuals with severe physical, mental and intellectual disabilities, particularly those residing inappropriately in congregate care and/or institutional environments, must be factored into planning while also ensuring that they are provided with opportunities to engage with 'readiness' and 'transition' activities.

Having said that, being made to wait for the implementation of the NDIS to effect any level of change for those people living in such environments is an insufficient response given their circumstances. Many who have lived in these facilities for significant lengths of time have little or no access to appropriate support to develop their skills and functional capacity, or to ensure their optimal social, emotional and physical well being. Living in completely inappropriate environments, they must be a priority for all levels of Government now.

# A. People with disability in health facilities in Qld – Findings of the Office of the Public Advocate

## People with disability in health facilities

The Public Advocate found that as at May 2013, there remained **271 people with intellectual disability or cognitive impairment residing in health facilities**, inclusive of mental health services, in Queensland. Most, but not all, of these people have complex or severe physical, medical or intellectual disabilities.

While acknowledging the individual circumstances of each resident, those who remain in long-stay health care facilities can be broadly characterised within two groups:

- First there are many people, notably people with intellectual disability, who ‘missed out’ on earlier deinstitutionalisation and have remained living in institutions for up to 65 years. Many were initially placed in these institutions as babies or small children, but for various reasons were denied the opportunities that were given to other people with similar levels of disability to live in the community. Others came to these facilities later in life following a breakdown in supports and/or the inability to access the necessary services to be supported in the community.
- Second, there are people with acquired brain injuries (ABI) residing in hospitals and other health facilities who are unable to access crucial opportunities for rehabilitation and reintegration back into community. Some have lived in these facilities up to 35 years.

Of the 271 people who were the subject of the report, **131 people** with intellectual disability or cognitive impairment are long-stay residents in **public health facilities** inclusive of residential health care facilities, Baillie Henderson Hospital and the Park Centre for Mental Health; a total of **12 people** are residing in **public aged care facilities**; and **30 people** are residing in **various hospitals and other health services**. A further **98 people** were residing in **mental health services**.

People with intellectual disability or cognitive impairment are residing for long periods of time in four main types of state government health care facilities in Queensland:

1. **Public residential health facilities:** These include places that were originally built for people with intellectual disability to reside such as Baillie Henderson Hospital (where people with intellectual disability have resided since it opened in 1890) and Halwyn Centre at Red Hill, as well as the Park Centre for Mental Health, Casuarina Rehabilitation Centre and the Jacana Acquired Brain Injury Services at Bracken Ridge and Brighton. This group of facilities has the largest proportion of people with intellectual disability or cognitive impairment residing in them. **(131 people/49% - see Table 1)**
2. **Public aged care facilities:** The Department of Health continues to operate a small number of public aged care facilities. People under 65 years with intellectual disability or cognitive impairment are residing at Eventide (Charters Towers), North Rockhampton Nursing Centre and the Moreton Bay Nursing Care Unit. This group of facilities have the smallest proportion of people with intellectual disability or cognitive impairment residing there. **(12 people/4%)**
3. **Hospitals and other health services:** There are also patients with intellectual disability or cognitive impairment in Cairns Base Hospital, Caboolture and Kilcoy Hospitals, Fraser Coast, Maryborough and Hervey Bay Hospitals, Gold Coast Hospital, Logan Hospital, Kirwan Health Campus, Princess Alexandra Hospital, Royal Women’s Hospital, and Redcliffe Hospital. Some of these hospitals, such as the Princess Alexandra Hospital, have specific Brain Injury Rehabilitation Units. **(30 people/11%)**

4. **Mental health services:** Queensland has a network of mental health services that include both in-patient treatment and support in the community. These services have the second-highest population of people with intellectual disability or cognitive impairment residing there. **(98 people/36%)**

**Table 1** Long-stay patients (under 65 years) with intellectual disability or cognitive impairment residing in public residential health facilities

	Baillie Henderson Hospital	Casuarina Rehabilitation Centre	Halwyn Centre	Jacana ABI Service (Bracken Ridge)	Jacana ABI Service (Brighton)	The Park Centre for Mental Health
Median age (years)	57	52	38	44	53	36
Youngest (years)	36	40	22	22	40	22
Eldest (years)	64	61	63	57	62	59
Females	17	<5	18	<5	8	<5
Males	9	<5	26	30	<5	5
Shortest length of stay (years)	10-15	<5	5-10	<5	5-10	<5
Longest length of stay (years)	60-65	10-15	30-35	30-35	10-15	10-15
Median length of stay (years)	40-45	5-10	25-30	15-20	10-15	10-15
Aboriginal and Torres Strait Islander	0	0	0	<5	0	<5
<b>Total = 131</b>	<b>26</b>	<b>8</b>	<b>44</b>	<b>33</b>	<b>12</b>	<b>8</b>

Source: Department of Health (July 2013)

## Models of care in health facilities

Consistent with a long tradition of institutional care for people with disability, premised on both a medical model of disability (which characterises disability as an illness) and a paternalistic approach (that is, a perception that people with disability need segregation from the community for their own protection), health facilities (inclusive of aged care facilities) do not meet contemporary standards for people with disability.

Health facilities are not ‘home-like’ despite the fact that many people with disabilities live there, some for most of their lives. Many people with disability in health facilities sleep in hospital beds in ward-type environments with other people. This is despite the fact that hospital beds are often not required for their disability (for example if they have an intellectual disability). It was submitted to the Public Advocate that the living conditions in one particular health facility:

**“directly contrasts how an ordinary home would look; dividing a multi-story building into living areas and providing sleeping arrangements where up to four people share a room is far from the ordinary home. Indeed, the centre is reminiscent of a nursing home which perpetuates the stereotype that people with a disability are sick and/or close to death.”<sup>1</sup>**

<sup>1</sup> This has been taken from a submission made to the Public Advocate regarding *People with Disability in Long-Stay Health Care Facilities*. The identity of this author has been suppressed for reasons of confidentiality.

This type of environment affords little privacy, even for family visits, and is often noisy. People are often restricted from seeking privacy or taking the opportunity for ‘down-time’ in their own rooms at particular times of day and, alternatively, are expected to congregate in one room, often with a television as the sole source of stimulation.

By their nature, health facilities are often staffed by nursing staff, allied health care professionals and other support staff, with a medical model of care predominating. This model of care and the often low ratio of staff to clients means that most of the day and the extent of engagement with staff is taken up with meals and personal care. This leaves little or no opportunity for individualised support and neither does it provide opportunities for people with disability to develop skills in the activities of daily living, nor even to have the opportunity to undertake tasks such as feeding themselves at dinner time.

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**“Because the nursing staff are often stretched for time it is not uncommon to see things being ‘done to’ the person with a disability as opposed to assisting, or working alongside them. For example, where an individual is able to eat independently, it is often far quicker if the worker feeds them. Not only does this impact on that person’s sense of independence, it also leads to loss of skills.”<sup>2</sup>**

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The size and nature of many of these facilities means that they operate according to strict routines, including strict eating times and strict times for bed (in one facility all residents, regardless of their age, had to be in bed by 6.30pm). Most decisions and choices are made ‘for’ residents. One staff member recounted the story of a woman who was relocated to community living after 13 years of waiting, and when she arrived at her new home she was asked ‘what would you like for lunch?’ The look on the woman’s face after being asked this question was deeply moving for the staff member, who acknowledged that this was the first time that the woman had been offered an opportunity to make a decision about her diet in 13 years.

People with disability in health facilities are often grouped together with others regardless of their ages, likes and dislikes, or level of ability. Access to the community is limited and for some non-existent. This results in a severe lack of social opportunities.

In these environments, people’s functional capacity often decreases. With things being done ‘to them’ and ‘for them’, they do not have the opportunities to learn how to care for themselves. Educational and vocational opportunities are often absent.

It was submitted to the Public Advocate that the cumulative effect of these conditions is that people experience deterioration in their health and wellbeing and lose crucial skills (including communication skills) that would enhance their ability to live a good life in the community.

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**“It is of great concern to me to witness how Sophie’s\* support needs have increased over time. Prior to being placed in the Centre she had limited speech, could feed herself, eat ordinary food once it was cut into bite sized pieces, walk small distances with support, support herself sitting up, and took minimal medication and had relative good health.**

**What I witness now is someone who has lost speech and language, lost ability to feed herself (eat and drink independently), lost ability to swallow solid food, lost all ability to walk, lost teeth, lost her good health (now taking many medications for systematic deterioration of eating, digestion, elimination), and her muscles have atrophied and stiffened.”<sup>3</sup>**

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<sup>2</sup> This has been taken from a submission made to the Public Advocate regarding *People with Disability in Long-Stay Health Care Facilities*. The identity of this author has been suppressed for reasons of confidentiality.

\* The resident’s real name and the name of the facility have not been used.

<sup>3</sup> Confidential, Submission No 7 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

## ‘Blocked’ pathways out of health facilities

### People with intellectual disability

There are a number of health facilities in Queensland where people with primarily intellectual disability reside. These include facilities such as Baillie Henderson Hospital in Toowoomba and Halwyn Centre in Brisbane, as well as Queensland’s network of mental health facilities.

There were 44 people with disability accommodated at the Halwyn Centre at the time of the Public Advocate’s inquiry, with a median age of 38 years. The youngest resident was 22 and the eldest 63. The median length of stay for residents of this facility was 25-30 years.

There were 57 people with disability accommodated at Baillie Henderson Hospital at the time of the Public Advocate’s inquiry, with a median age of 57 years. The youngest resident was 36 years and the eldest 64 years. The median length of stay for residents of this facility was 40-45 years.

Approximately 95 people with a sole diagnosis of either intellectual disability or cognitive impairment (that is no mental illness or dementia) lived in mental health services in Queensland at the time of the Public Advocate’s inquiry; 59 of whom had resided in the mental health facility over 10 years.

Many of this group ‘missed out’ on the first wave of deinstitutionalisation in Queensland and have remained living in inappropriate environments. It was noted that many of this group had resided there since they were babies or small children. Others have entered relatively recently, particularly as a result of their community living arrangements having broken down, and have remained there.

Given these facilities are operated by Queensland Health, they are ‘block funded’ and people do not have individual allocations of funding for their support. Residents of Baillie Henderson Hospital pay 66.67% of their disability pension as a ‘fee’ charged to reside in the facility. Their remaining income goes to personal effects and often needs to be spent on purchasing their own medical aids and equipment (as they are not eligible under the Queensland Government’s Medical Aids and Equipment Scheme). Sometimes, if they have sufficient residual income, they may use this to pay for additional support to enable their own community access.

At the time of the Public Advocate’s inquiry, many residents had never been assessed by Disability Services and even if they had, although they may be eligible to receive disability support services, they are often not prioritised for services given that they have ‘a roof over their head’.

### People with acquired brain injury (ABI)

In Queensland, people who have an accident or other trauma will usually be treated initially and medically stabilised in a hospital – that is, an acute health facility. Once they are medically stabilised, depending on the nature of their brain injury, an intense period of rehabilitation should begin.

Yet to access this all important rehabilitation, people need to find services that are equipped and adequately funded to provide rehabilitation and, depending on their circumstances, accommodation and support whilst they access rehabilitation.

Unfortunately many people with ABI, while waiting for appropriate rehabilitation services, spend their time in acute hospital beds, without receiving the important rehabilitation they need.

A survey conducted by the Department of Health in March 2012 identified that there were **64 people with a disability in acute hospital beds** in Queensland waiting to transition to community living:

- **46 people** had been in hospital for **up to 12 months**;
- **10 people** had been in hospital for **12 months to three years**; and
- **7 people** had been in hospital for **between 3 to 10 years**.<sup>4</sup>

<sup>4</sup> Department of Communities, Child Safety and Disability Services and Department of Health, Submission No 21 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 6 September 2013, 6.

Many patients who are unable to access a bed in a rehabilitation service or other appropriate supported accommodation setting may ultimately be discharged into the care of their families, or may enter aged care facilities.

Aged care in many cases becomes the default system of care, although it is inherently unsuited to, and inappropriate for, younger people with acquired brain injuries.

In the past some people with ABI may have been transitioned to a bed in a 'step-down' or 'slow-stream rehabilitation centre'. In Brisbane, these included Casuarina Rehabilitation Centre in Wynnum and the Jacana Acquired Brain Injury Services in Bracken Ridge and Brighton. Unfortunately, given the lack of appropriate pathways from these services, these services have been forced to operate as more permanent facilities and ultimately have become long-stay residential services for people who should have moved into the community a long time ago.<sup>5</sup>

For example, at the time of the Public Advocate's inquiry there were **33 long-stay residents in the Jacana Acquired Brain Injury Service** at Bracken Ridge, with the median length of stay for patients being 15-20 years and the **longest length of stay 30-35 years**. There were also **12 people in Jacana Acquired Brain Injury Service Brighton** and **8 people in Casuarina Rehabilitation Centre** who were long-stay residents of these facilities.

#### **Jacana Acquired Brain Injury Service**

While the Jacana Acquired Brain Injury Service was originally established as a residential service for young people with acquired brain injury, its overall aim is as a slow-stream rehabilitation service.

It has now, however, become predominately a residential service because it has been 'bed blocked' for many years.

Of the total of 37 residents, only 4 people are on a 'slow to recover rehabilitation program'. The other residents (33 in total) have been there for long periods of time waiting for funding to move into community living, with the longest length of stay 30-35 years and the median length of stay 15-20 years. This 'bed blockage' stops other people from being admitted for short-term rehabilitation.

While there is a committed recreational officer and professional allied health workers, it is acknowledged that living for this length of time in a hospital-like environment is not good for residents.

Some residents have managed to secure limited funding from disability services for community access, but many have not. In a few cases, because of the lack of funding available from disability services, residents have grouped together to pay for community access themselves out of the limited discretionary income that they have left over from their disability pensions. One man who was part of this arrangement was told by the Public Trustee that he could no longer afford to pay for these services. Faced with the idea that this man would now no longer be able to access the community, the non-government organisation provided this service for free.

Staff state that the main barrier to utilising Jacana Acquired Brain Injury Service as a rehabilitation service (as was intended) is the lack of accommodation and support services for people to move on to, but in particular the lack of coordination from disability services and housing. Very often, particularly in the past, a person might be successful in having housing allocated but no support from disability services would be available (or the other way around). Given the lack of alternatives, many people with disability often end up exiting these facilities into aged care facilities.

<sup>5</sup> Young People in Nursing Homes National Alliance, Submission No 19 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 20 August 2013, 11.



## Bed blockage – the cost to the system

The current system in Queensland is hampered by persistent bed blockages, which have flow-on effects ultimately resulting in people with ABI ‘living’ in services meant for intensive short-term rehabilitation, as well as living in acute hospital beds and mental health services.

The bed blockage in the rehabilitation services (or downstream blockages) means that pressure starts to build up in acute hospitals as the next wave of people with ABI have nowhere to go. This also creates a situation where many people with ABI are discharged from hospital into the care of their families without rehabilitation or support, or into aged care facilities.

Many places that may have been intended as slow-stream rehabilitation services have unfortunately become long-term destinations with people residing there for as long as 35 years. This stops these facilities from operating as short-term rehabilitation services, services much needed in Queensland.

Long-term stays in acute hospital units represent a significant cost to the public health care system, with the Quarterly Brain Injury Services Meeting Group (QBISM)<sup>6</sup> highlighting that evidence to support the cost-effectiveness of supporting adults with ABI and high care needs in the community is clearly documented.

QBISM conducted an analysis of the costs associated with significant delays in securing community living options for adults with high care needs exiting in-patient rehabilitation units without access to compensation for their injuries. They compared case studies of people who did not receive compensation for the accident that caused their ABI and people who did receive compensation. Those who did not have compensation, but instead were forced to rely on the Queensland Government to respond to their care needs, not only experienced significant delays in their transition to community-based supported accommodation, but also cost significantly more to support due to their extended stay as a sub-acute in-patient.

**Table 2** Estimated costs of delayed transitions through the rehabilitation continuum

Phase of Care	Case Study 1 - Client with severe head injury	Case Study 2 - Client with severe complex head injury
Compensation	None	Awarded
Acute in-patient admission	34 days @\$1,200 per day \$40,800	266 days @\$ 1,200 per day \$319,200
Sub-acute in-patient rehabilitation	694 days @ \$1,200 per day \$832,800	241 days @ \$1,200 per day \$289,200
Delay to next phase of care	412 days	Nil – funded by Workcover
Community-based accommodation and rehabilitation	Not applicable awaiting supported accommodation	Ongoing case management 6-7 sessions of community-based therapy per week @ \$158 per hour 24/7 in-home care program – Approx \$5,200 per week
Estimated additional costs related to delay to community	\$325,000 over 412 days	Nil
Summary	Currently waiting for 412 days in sub acute hospital bed for transition to community and rehabilitation Cost: approx \$1,200 per day	Currently in supported accommodation receiving weekly therapy and 24/7 support and case management Cost: approx \$486-\$885 per day

**Source:** Quarterly Brain Injury Services Meeting (QBISM) Group, *A Comprehensive Service System for Queenslanders with Brain Injury, Positioning Paper* (August 2013).

<sup>6</sup> QBISM has representation from the Princess Alexandra Hospital Brain Injury Rehabilitation Unit (BIRU), the Acquired Brain Injury Outreach Service (ABIOS), Casuarina Rehabilitation Centre Rehabilitation Centre Rehabilitation Centre, Jacana Acquired Brain Injury Service Acquired Brain Injury Service, The Royal Brisbane and Women’s Hospital Neurosurgical Unit, South East Queensland Mental Health Clinical Cluster, Brighton Sub-Acute Service, Baillie Henderson Hospital Toowoomba, the Motor Accident Insurance Commission of Queensland (MAIC), the Department of Communities, Work Cover, CRS Australia, Synapse, Open Minds, National Disability Services, Sporting Wheelies, Reability, Edge Rehabilitation, Coastal Rehab, Integrate Rehab, Neuro Rehab Solutions, BE Lifestyle, The University of Queensland, Griffith University.

The analysis conducted by QBISM indicates that it cost significantly more to care for a person as an acute/sub-acute in-patient in a hospital than it did to support a person to live in the community with appropriate support, therapy and rehabilitation.

QBISM approximated that it cost \$1,200 per day to care for a patient in a sub-acute hospital bed. Conversely, the cost of supporting a person to live in the community was calculated to range from approximately \$486 per day (which includes 8 hours of support per day and 6 one-hour sessions of private therapy) up to approximately \$885 per day (which includes 24 hours a day/7 days a week support and 6-7 one-hour sessions of private therapy each week).

However, any analysis of the cost to the system of delays in receiving rehabilitation must also consider the lifelong expenses associated with failing to provide a person with appropriate rehabilitation in a timely way and having persons reside in acute or sub-acute settings for lengthy periods. It has been established that early and sustained access to rehabilitation after ABI helps to reduce disability, restore function and improve participation.<sup>7</sup> This is further explored below.

## Bed blockage – the cost to the person

People with ABI who remain in institutions (including aged care facilities) for long periods of time experience significant deterioration in their health and wellbeing as a result. It can also lead to a loss of important functional abilities, including continence and mobility skills, some of which may have been regained in their initial hospital-based rehabilitation. The loss of these skills not only increases future care costs, but can also limit community service discharge options and lead to further time in acute care.<sup>8</sup> In other words, the longer a person stays in an institutional environment, the more complex and costly they become to support in the community. Therefore, the likelihood of independent living diminishes over time for that person.

This point was made to the Public Advocate’s inquiry by the Young People in Nursing Home Alliance (YPINHA):

“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 circumstances, as detailed below, demonstrate the loss of capacity that is common in long-stay in-patients.

This young man was in his early 20s when he lost control of his vehicle and crashed. When this young man entered the service on discharge from acute care, he had made a good recovery from the car accident, which 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 in his remaining hand, as this would deny him the capacity to drive his electronic wheelchair, the only semblance of independence he has left. The tendon releases in his ankles means he will never be able to walk independently. He now requires permanent 24-hour support.

<sup>7</sup> QBISM Group, above n 3, 19.

<sup>8</sup> Young People in Nursing Homes National Alliance, Submission No 19 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 20 August 2013.

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 listed on the Department of Communities, Child Safety and Disability Services' (DCCSDS) Register of Need (RON), DCCSDS had indicated, at the time of the inquiry, that they have no capacity to provide a response at this time or in the immediate future.

Similarly people with intellectual disability who reside for long periods of time in institutional type environments also lack the opportunities to build capability over a range of areas important for daily living, and importantly lose existing skills. This ultimately impacts on opportunities for and the costs of their future care.

Parents of a man with intellectual disability who has been living in a health facility for 25 years submitted to the Public Advocate their concerns about the impact on their son of living in an institutionalised environment.

These parents describe the care provided to Stuart\* as being like hospital care. For example, everyone eats together, the same thing at the same time. Everyone must go to sleep at the same time, early evening, despite their age. All residents sleep in hospital beds. Stuart has slept in a hospital bed in a ward-like environment for the past 25 years, even though this is his 'home'. He does not get any opportunity to learn daily living skills like cooking, as the staff do everything for him.

They described how over the years their son had not only been denied the opportunity to learn and develop, but that he has greatly deteriorated. For example, despite his non-verbal status, when Stuart was younger, they said, he showed more potential for understanding written words and numbers and even had an interest in maths.

However the facility where he resides has never worked to develop this potential or even to provide assistance with communication. They believe that despite his 'limitations' even now, after 25 years of living in the facility, Stuart is capable of doing more than he currently does.

Stuart's parents believe their son should be living in the community and could live in the community with support and appropriate accommodation. They were concerned, however, that their son should not be placed in another institutional-type environment, for example in a home with other people with disability.

While assured of anonymity, the parents were greatly concerned not to be identified because they believed in some way it would affect their son's support. At the time of the Public Advocate's inquiry the family were still waiting on funding for Stuart to move out of the facility, but were getting older, and growing more concerned for his future.

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\* The resident's real name and the name of the facility have not been used.

## B. Options, consequences and considerations for deinstitutionalisation

### Context for deinstitutionalisation – transitioning to the NDIS

The provision of disability services is in enormous flux with the launch of the NDIS and the states and territories within Australia preparing to divest themselves of responsibility for the delivery of disability services.

While recognising the importance and opportunity presented by the NDIS, the Public Advocate has many concerns about the transition to the NDIS for people with disability. Paramount to this is the need for appropriate safeguards to enable effective oversight of the new disability system and ensure quality services and supports for people with disability as well as their safety and well-being.

People with severe physical, mental or intellectual disabilities are particularly vulnerable in this process of NDIS readiness and transition, and must be provided with opportunities to develop transition plans and participate in readiness activities. The Public Advocate is concerned however that many people with severe physical, mental or intellectual disabilities who are living in aged care facilities or health facilities are not being adequately factored into the planning and transition process in the same way as other people with disability.

In Queensland, for example, the Public Advocate has received anecdotal advice from non-government agencies who are facilitating NDIS readiness activities with people with disability and their families suggesting that they have been told not to engage people with disability living in certain health care facilities. Further, in attending a recent Board meeting in one of the Health and Hospital Service districts, the Public Advocate was concerned by the limited understanding about the NDIS that was conveyed by many Board members.

Many of the people in health care facilities in Queensland do not have current or up-to-date assessments. Many would not be on the Register of Need for disability services. Sometimes this is because of the mistaken belief/assumption that their needs are currently being taken care of, or that they would not be suitable for transition out of health facilities or aged care facilities due to their high needs.

In response to the Public Advocate's inquiry, the Queensland Government commenced a Joint Action Plan, part of which involved commencing the identification of all long-stay patients in health facilities, as well as undertaking collaborative, individualised and person-centred assessment and planning for those people 'willing to engage with the plan partners'. This work must be a priority in each state and territory in planning for and transitioning to the NDIS and must also extend to people with severe physical, mental and intellectual disabilities residing in aged care facilities.

At the same time, people currently living in institutional environments should not have to wait until full transition to the NDIS for appropriate accommodation and support. State and territory governments must make it a priority to undertake individual assessments of all people with disability currently living in health and aged care facilities, and begin working with them to plan their transition to the community.

This process should also aim to identify systemic issues that may impact successful transition, including but not limited to identifying any areas in which there is a need to develop sector capability and/or community infrastructure to support and enable true 'choice' for NDIS participants.

## Principles for deinstitutionalisation

### ***Convention on the Rights of Persons with Disabilities***

Residential environments for people with disability, including severe physical, mental and intellectual disabilities, must be provided in a way that is consistent with contemporary standards of support for people with disability and should also be consistent with the objectives of and obligations in the *Convention on the Rights of Persons with Disabilities* (the Convention).<sup>9</sup>

Of significance to any consideration of appropriate residential care arrangements for young people with severe physical, mental or intellectual disabilities is the more recent paradigm shift heralded by the Convention, which promotes a new way of thinking about disability.

Underpinned by what is known as the ‘social model of disability’, the Convention incorporates a contemporary approach to disability and emphasises the importance of:

- recognising that disability is an evolving concept and that disability results from the interactions of people with impairments with attitudinal and environmental barriers;
- the right and capacity of people with disability to make valued contributions to their communities; and
- recognising that all categories of rights apply to people with disability, who should therefore be supported to exercise those rights.

A number of articles in the Convention provide for specific obligations of State Parties in relation to people with disability living segregated in health facilities. Article 19 of the Convention specifically addresses the concept of independent living and inclusion in the community, and directs State Parties to ensure that:

- persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and
- community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.<sup>10</sup>

Read with Article 5, an overarching principle relating to equality and non-discrimination, there is an obligation on State Parties to ensure support is provided to people with disability to enable them to live in the community with others, not segregated in health facilities, as a means by which to avoid discrimination.

Article 26 also imposes an obligation on State Parties to ensure the provision of habilitation and rehabilitation services and programs that will enable people with disability to attain and maintain maximum independence and full physical, mental, social and vocational ability.

The new paradigm shift heralded by these and other articles of the Convention has also contributed to the movement away from treatment, care and protection, towards acceptance of impairment as part of the diversity of our community.<sup>11</sup>

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<sup>9</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, [2008] ATS 12 (entered into force 3 May 2008) (*‘Convention on the Rights of Persons with Disabilities’*).

<sup>10</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, [2008] ATS 12 (entered into force 3 May 2008) (*‘Convention on the Rights of Persons with Disabilities’*).

<sup>11</sup> P French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) *Human Rights Law Review* 8.

Furthermore, there is now an understanding that people with disability have the same human rights as us all, should not be segregated from the community, and can and should be supported to make their own decisions about their lives.

Models of care based on segregation and paternalism are now viewed as anachronistic and dehumanising. There is an emphasis on habilitation and building the capability of people with intellectual disability or cognitive impairment, based on a growing understanding that “not all ‘mentally disabling conditions’ remain static, and that decision-making abilities can be developed, retained or, in some circumstances, exercised with assistance.”<sup>12</sup> Community living, with personalised and appropriate supports, is central to this approach.

There must be a commitment by state and Commonwealth governments (including the NDIS) to the delivery of disability supports and services in a manner that is consistent with the Convention.

### **Building accessible and inclusive communities**

In line with the obligations for state parties in the Convention to make reasonable accommodations to prevent discrimination against people with disability, there must be a significant effort made by all levels of government to build accessible and inclusive communities.

This means that the range of services and facilities that people without disability access including health, education, housing and transport for example also need to be accessible and responsive to people with disability including people with severe physical, mental or intellectual disabilities.

The lack of accessible and inclusive communities not only contributes to the social isolation of people with disability but also creates barriers to deinstitutionalisation, including by limiting opportunities for young people with disability who are inappropriately placed in aged care facilities.

The Productivity Commission (PC) in its Report *Disability Care and Support*,<sup>13</sup> identified the importance of the inclusion of what it termed Tier One and Tier Two services. Tier One services were those that promoted accessible communities for people with disability, including promoting awareness. The PC envisaged that the work of the NDIS would complement work undertaken by all levels of government, other agencies (such as the Human Rights Commission) and non-government organisations.<sup>14</sup>

The PC also understood that specialist disability services (provided under Tier Three) were only some of the services that people with disability would need to access. Like people without disability, people with severe physical, mental and intellectual disabilities also have to access a range of other services such as health, housing, transport and education services to name but a few. Tier Two services were described as those that assisted people with disability gain access to all the services they need in addition to specialist disability services.

The Public Advocate is concerned about the transition to the NDIS and, under the full scheme, who will continue to take responsibility for driving the creation of inclusive and accessible communities and the importance of including people with severe physical, mental and intellectual disabilities in this work.

Currently many states have strategic policy infrastructure, resources and frameworks to underpin this work in partnership with the Commonwealth Government under the National Disability Strategy in accordance with the National Disability Agreement.

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<sup>12</sup> R Creyke, *Who Can Decide? Legal Decision-Making for Others* (Department of Human Services and Health, Aged and Community Care Division, Commonwealth, 1995) 38.

<sup>13</sup> Productivity Commission, *Disability Care and Support* (Inquiry Report, Volume 1, no 54, 31 July 2011).

<sup>14</sup> Productivity Commission, *Disability Care and Support* (Inquiry Report, Volume 1, no 54, 31 July 2011) 161.

In Queensland, the government has released a *Queensland Disability Plan 2014-2019*. While a big focus of the plan is about transitioning Queensland to the NDIS, priority six is about enhancing ‘mainstream services and facilities to enable genuine choice and participation in areas including education, employment, health, justice services and housing’. Further under the *Disability Services Act 2006* (Qld), each Queensland Government department is required to have a Disability Services Plan, setting out actions to improve access to government services and provide appropriate services to people with disabilities and their families. There is a current question mark about the agency that will continue to do this work under the NDIS, without which people with severe physical, mental and intellectual disabilities will be particularly vulnerable to social isolation and continuing institutionalisation.

Yet, even with this current emphasis on inclusiveness, more needs to be done, particularly for people with severe physical, mental and intellectual disabilities. The Public Advocate identifies three key areas as being crucially important for deinstitutionalisation and for mitigating against young people continuing to be inappropriately placed in aged care facilities, noting that there is a need to immediately improve accessibility, inclusiveness and responsiveness in these areas. These include:

- housing;
- health services; and
- rehabilitation services.

### **Housing**

The lack of appropriate accommodation options is one of the main barriers to people with severe and complex disabilities living in the community and contributes to protracted stays in hospitals, rehabilitation services and aged care services, and/or to ‘place shifting’ between these environments.

People with disability are currently waiting very long times (sometimes years) for appropriate housing to become available. While the NDIS might provide people with funding to purchase the support they need to live in the community, without extra investment in appropriate and accessible housing now, there will be nowhere for them to move to.

Preparation for this necessary systems response and development of infrastructure must begin now.

The Public Advocate considers that there must be increased government investment in a range of appropriate accommodation options for people with disability. This investment needs to be informed by consultation with relevant stakeholders, including people with disability and their family members.

This investment must also take into account recognised best practice in accommodation for people with disability in the community and research into what provides the best outcomes in terms of social and emotional wellbeing, opportunities for choice, and participation in the community. This must incorporate learnings generated from longitudinal research on the outcomes for people who were deinstitutionalised as part of the first wave of deinstitutionalisation.

This is not to suggest that all people with severe disability (particularly people with intellectual disability or cognitive impairment) currently residing in health care facilities would require purpose-built or designed, or even modified, accommodation. However there is a need to ensure an appropriate mix of options is available so that housing does not become the system blockage that prevents these individuals from maximising their opportunities for social and economic participation under the NDIS.

The focus on housing needs to include a broader focus on accessible and inclusive communities, including urban design and universal housing design to ensure that people with disability do not continue to be segregated in ‘disability housing,’ but have the opportunity to become part of vibrant and inclusive communities.

## Health services

Due to advances in medical technology, as well as the severity of some people's disabilities, there is a growing number of people with significant impairments and a range of clinical needs who may be beyond the usual capability of the existing human services system. It was submitted to the Public Advocate in the 2013 inquiry that the development of tightly controlled and separate program areas comprised of health, housing, disability and aged care can result in rigid program boundaries.

The central issue for many people with severe physical disabilities and other complex health and/or medical needs is that the health system does not accept responsibility for the ongoing management and oversight of health needs outside of health care facilities. Rather, the health system seeks to discharge responsibility for that management and oversight to other areas of the service system that would require enhanced capability in order to appropriately support such needs. This can have catastrophic results for individuals who, as a result of inappropriate or inadequate supports and services, may find themselves in crisis and subsequently be re-hospitalised or placed in aged care facilities, or alternatively may experience a steady deterioration in their health and wellbeing.

This points to an urgent need for a better connection between health and disability support services to ensure that people do not risk repeat episodes of hospitalisation and long in-patient stays and, instead, can access the necessary supports and services to remain in community and maintain their health and wellbeing over the long-term.

## Rehabilitation services

Submissions to the Public Advocate as part of the inquiry into people with intellectual disability and cognitive impairments in health facilities indicated that there is currently a paucity of rehabilitation services for people with acquired brain injury, particularly in Queensland.

It was argued that, outside the private system, rehabilitation services do not exist in the quantity or type needed to satisfy the growth in demand in Queensland.

Numerous stakeholders submitted that rehabilitation, across a range of areas, is needed across the life course of a person following an ABI. Different individuals require different services at different stages in their recovery. Therefore a coordinated and flexible approach is required given the changing nature of a person's needs as they recover from brain injury.

The QBISM group submitted that:

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*"Subsequently, services need to be re-accessible, and coordination and communication between different services along the rehabilitation continuum is an essential component of effective rehabilitation. Access to multidisciplinary teams with specific expertise in brain injury rehabilitation improves long-term outcomes, decreases care needs and has the potential to significantly reduce long-term care costs."*<sup>15</sup>

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Rehabilitation may sometimes be provided as an in-patient service, depending on the needs of the person, but it is argued that, for the most part, rehabilitation needs to be provided in the same location as the patient who is living in the community.<sup>16</sup>

This requires the availability of allied health care staff to provide rehabilitative services and other necessary therapy support in the community.

There also needs to be a coordinated and flexible approach to rehabilitation services that reflects that individuals will require access to different types of rehabilitation, at different times across their life course. Services need to be re-accessible, and communication and coordination across the different rehabilitation services is essential.

<sup>15</sup> Quarterly Brain Injury Services Meeting (QBISM) Group, *A Comprehensive Service System for Queenslanders with Brain Injury, Positioning Paper* (August 2013) 19.

<sup>16</sup> Young People in Nursing Homes National Alliance, Submission No 19 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 20 August 2013, 15.



## Individualised and person-centred responses

It is important that people in health facilities are able to access individualised funding (that is funding allocated to them personally) and to have their needs regularly re-assessed. This is consistent with contemporary and accepted standards of providing funded support to people with disability. It is also the standard that will be upheld through the NDIS.

There is a danger of ‘defining’ these individuals (including people with disability in aged care facilities) as a collective group without considering the capabilities, needs and goals of each person individually. For example, the individuals currently residing in long-stay facilities and aged care facilities are often described as a ‘cohort’ who have high and complex health and associated support needs that require specialist medical support, with suggestions that the support required is not readily available in the community.

Individual assessments must be undertaken with each resident currently residing in long-stay facilities and aged care facilities. Each resident should be considered on an individual basis, like other people with disability who are assessed for their need for support and services, and they should not be seen as part of a ‘cohort’ or ‘group’ with an assumption that they have the same level of need.

Many people also commented to the Public Advocate that the current systems for allocating ‘support packages’ are inflexible and wasteful. It is noted that for people with acquired brain injuries in particular, support needs change over their life course with more intensive support required at some stages and less at others. Once their medical condition is stabilised following their injury, they may require intensive rehabilitation, then perhaps a ‘top up’ every now and again.

Currently, it seems that people’s needs are assessed at a certain level and in some instances they receive a very expensive package that is in fact not always required consistently, nor in an ongoing way, throughout their lives.

It is also imperative that these assessments incorporate consultation with, and the participation of, individuals, their family members, staff and any advocates or external service providers who engage with them. The assessment process should also consider the extent to which each person’s needs could be better met in a community-based support arrangement.

Each person must have the opportunity to actively participate in their own assessment and transition planning. Information must be provided in accessible formats and people must be supported in their decision-making with respect to deciding options for the future. It is imperative that each person has the opportunity to discuss their needs and goals, nominate the type of accommodation they would like to live in and who they would like to live with, and decide the types of supports they would like to live the life they want. This is important for maximising their autonomy and choice.

Family members must also be engaged, kept informed and involved, have the opportunity to voice their wishes and concerns, and have the opportunity to provide input into assessment and planning. In particular, individuals and their families must have certainty about the plans for the future and what is on offer so that they can make informed decisions.

## Learning from the past

Many commentators reflecting on past deinstitutionalisation reforms have cautioned against measuring the success of deinstitutionalisation by the numbers of people who leave institutions.<sup>17</sup> Community living is not solely about a geographical location.<sup>18</sup>

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**Importantly, as the sister of a long-stay health facility resident told the Public Advocate, people need to “live in a place that they can call ‘home’ in the true sense of the word.”<sup>19</sup>**

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<sup>17</sup> L Chenoworth, ‘Closing the Doors: Insights and Reflections on De-Institutionalisation’ (2000) 17(2) *Law in Context* 77, 90.

<sup>18</sup> L L Bachrach, ‘A Conceptual Approach to Deinstitutionalization of the Mentally Retarded: A Perspective from the Experience of the Mentally Ill’ in R H Bruininks et al (eds), *Deinstitutionalization and Community Adjustment of Mentally Retarded People* (AAMD Monograph No 4, Washington, DC: American Association on Mental Deficiency, 1981).

Without appropriate support, negative outcomes for people with disability moving into the community can include homelessness, or what can be seen as ‘reinstitutionalisation’, whereby they may end up in prison, nursing homes or psychiatric hospitals, or move between these facilities.<sup>20</sup>

Not all studies show consistent and universally favourable outcomes for people moving from an institutional setting into community living. In a comprehensive review of deinstitutionalisation and community living in Scandinavia, the United Kingdom and the United States, it was found that despite good empirical evidence for better conditions in community-based facilities, considerable variations existed for individuals.<sup>21</sup> Similar findings have been found in Australian studies, with good outcomes for people often being dependent on the nature of the opportunities and services provided in each community setting.<sup>22</sup>

A long-term study of people relocated from Challinor Centre (an institution for people with intellectual disability in Queensland) found that although there had been good outcomes for many people, not all had progressed to living integrated lives in the community. This was more likely to be the case where the alternative residences they were relocated to were also institutional in character, where residents were not encouraged to form relationships with local neighbours, shop-keepers and business people, and where they had their activities limited to socialising only with other people with intellectual disability.<sup>23</sup>

There is also evidence that in deinstitutionalisation reforms there is often a tendency for those with the most complex needs to be left for last. These people may include those with a dual diagnosis (ie. intellectual disability and mental illness), people with high and complex needs, or those labelled as having ‘challenging behaviours’. Chenoweth argues “these are the people who often remain after the funding for deinstitutionalisation has ceased”, and comments that those who did not move out after the first wave of deinstitutionalisation often missed out.<sup>24</sup> Of those left behind after the wave of deinstitutionalisation, many are ageing, and may transition from a health facility to an aged care facility without the chance for community living.

### Appropriate destinations

Studies of deinstitutionalisation in Australia also indicate that careful consideration should be given to the type of accommodation people are relocated to. The outcomes for adults with moderate to severe intellectual disability and challenging behaviours in community group homes were compared to those relocated to cluster centres and it was found that “although both cluster centres and community group homes showed improvements over the institutional setting, dispersed community houses offered increased opportunities for choice-making, acquisition of adaptive behaviours and improved life quality”.<sup>25</sup>

While there is strong evidence to suggest that smaller, dispersed community housing tends to provide more opportunities and improved outcomes for people,<sup>26</sup> no one single model stands out as the ideal model.

*The Best Practice Framework for the Provision of Community-based Accommodation and Support for People with a Disability*, developed by the Centre for Developmental Disability Studies, states that best practice in service delivery would offer people a range of accommodation and support options

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<sup>19</sup> Confidential, Submission No 7 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

<sup>20</sup> L Chenoweth, ‘Closing the Doors: Insights and Reflections on De-Institutionalisation’ (2000) 17(2) *Law in Context* 77, 86.

<sup>21</sup> J Mansell and K Ericsson (eds), *Deinstitutionalization and Community Living: Intellectual disability services in Britain, Scandinavian and the USA* (London: Chapman & Hall, 1996).

<sup>22</sup> L Young, A Ashman and P Grevell, ‘Closure of the Challinor Centre II: An Extended Report on 95 Individuals after 12 Months of Community Living’ (2001) 26(1) *Journal of Intellectual and Developmental Disability* 53,52.

<sup>23</sup> L Young, A Ashman and P Grevell, ‘Closure of the Challinor Centre II: An Extended Report on 95 Individuals after 12 Months of Community Living’ (2001) 26(1) *Journal of Intellectual and Developmental Disability* 53,176.

<sup>24</sup> L Chenoweth, ‘Closing the Doors: Insights and Reflections on De-Institutionalisation’ (2000) 17(2) *Law in Context* 77, 88.

<sup>25</sup> L Young, ‘Community and Cluster Centre Residential Services for Adults with Intellectual Disability: Long-Term Results from an Australian-Matched Sample’ (2006) 50(6) *Journal of Intellectual Disability Research* 419.

<sup>26</sup> T R Parmenter and S R C Arnold, *Disability Accommodation and Support Framework Report* (Centre for Developmental Studies for the Victorian Department of Human Services, 2008) 31; J L Young, *De-Institutionalisation and Changes in Life Circumstances of Adults with Intellectual Disability in Queensland* (Unpublished PHD Thesis, School of Education, University of Queensland, 2000) 176.

to suit their preferences and needs, which may change over their lifetime.<sup>27</sup> Although it must be stated that many submissions to the Public Advocate as part of the inquiry into long-stay health care facilities cautioned against, or were absolutely opposed to, moving people from institutions to congregate-living facilities in the community.

Evidence indicates that there must be a community-based approach to planning with a concomitant focus on the individual, including their interrelationships with people in the institution from which they are relocated, their family and friends, and their abilities, aspirations and available supports. While ‘top-down’ policy decisions can be made to relocate people from institutions, the process of planning for and relocation of people must be a ‘bottom-up’ process,<sup>28</sup> in which appropriate time and resources are devoted to making the relocation successful for the person with disability.

### **Coordinated and joined up services and supports**

Although planning has to happen with the person and their family within the context of local community, many commentators in the Public Advocate’s inquiry spoke to the importance of high level support in each department for a collaborative and coordinated response.

The work that is presently involved to get a person out of an institution takes years of planning, with ‘hit and miss’ opportunities for aligning a person’s housing and support needs. Sometimes housing will be available, but not support and vice versa. This is frustrating, time consuming and, as it was reported to the Public Advocate, a very inefficient way for local government and funded non-government staff to operate.

Many people at the local level felt hampered by the lack of support for their initiatives by the senior executive of departments. Locally based coordination between departments and services is to be commended but must have support at the highest levels of all relevant departments, including but not limited to those departments responsible for health, housing and disability services. Ideally support should be enabled by a whole-of-government commitment.

Concern was expressed that despite the extra injection of funds that may come with the NDIS, unless systems work together in an integrated way, people with severe disabilities may continue to find themselves in crisis, stuck in health care facilities or returned to such facilities when transition to community-based living fails and the person and their family are in crisis.

The need for skilled coordinators, based in the community, who could oversee the integrated service response and negotiate a person’s pathway through the service system was also identified. For those with acquired disabilities, case coordinators should link with people soon after their injury, assist with discharge planning and facilitate access to the types of community-based accommodation, support, therapy and rehabilitation that they need. They should also play a role in building and maintaining people’s links with their natural community support networks.

## **What is happening in Queensland**

The Public Advocate’s report – *People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation* – was tabled in the Queensland Parliament on 7 November 2013.

The Public Advocate made a number of recommendations in Part 7 of the report including, amongst others, that there should be:

- an Action Plan developed to support people with intellectual disability or cognitive impairment who remain living in health facilities to access more appropriate and inclusive supports and

<sup>27</sup> T R Parmenter and S R C Arnold, *Disability Accommodation and Support Framework Report* (Centre for Developmental Disability Studies for the Victorian Department of Human Services, 2008) 31; 10-11.

<sup>28</sup> F Maddison, *Disability, Institutional Reform and De-Institutionalisation: The Queensland Experience* (Unpublished MA Thesis, Department of Anthropology and Sociology at the University of Queensland, 1998).

- services and to enable them to transition out of long-stay health care settings and into appropriate community-based accommodation where appropriate and desired; and
- consideration for the needs of these individuals in the phased approach to the National Disability Insurance Scheme.

## **What has happened since the report was tabled?**

### **The Queensland Government**

In 2013 the then Queensland Government commenced the development of a Joint Action Plan – *Transition of long-stay younger people with a disability from Queensland public health facilities* (the Joint Action Plan). This Joint Action Plan was being developed in partnership between the Department of Communities, Child Safety and Disability Services (DCCSDS), Queensland Health and the Department of Housing and Public Works (DHPW). A Steering Group comprising representatives from DCCSDS, Queensland Health and DHPW as well as the Department of Premier and Cabinet and Queensland Treasury and Trade was established to oversee the work undertaken as part of the plan.

### **Queensland Health**

In December 2013, the Director-General of Queensland Health wrote to all Hospital and Health Boards to ask them to collaborate with their regional counterparts from DCCSDS and the DHPW to support the Joint Action Plan. As a result, Queensland Health reported that as at 30 June 2014 this collaboration has enabled 25 long-stay younger people with a disability to be supported to move from Queensland public health facilities to more appropriate living arrangements in the community.

Amendments have also been made to the *Hospital and Health Boards Regulation 2012* to provide for the disclosure of patient information to nominated Government entities which will facilitate the sharing of relevant client data with DCCSDS and DPWH to support action under the Joint Action Plan as well as allow preparation for the implementation of the National Disability Insurance Scheme (NDIS) in Queensland.

### **Department of Communities, Child Safety and Disability Services (DCCSDS)**

DCCSDS reported that the Joint Action Plan partners were developing a protocol to support and enhance collaboration locally and support more robust person centred planning processes. It was proposed that this inform the key actions that were planned for 2014-15, which will focus on identifying all long-stay patients, as well as undertaking collaborative, individualised and person-centred assessment and planning for those people who wish to engage with this process. DCCSDS viewed this work as important in ensuring current and accurate information about these individuals, thus enabling the resources required to support transition to community living to be identified.

In 2013-14, \$2 million was allocated to support transitions.

### **Community groups and alliances and local action**

Importantly, the issue is also being driven by a variety of community organisations and alliances.

A number of community forums have been held bringing together government and non-government agencies, advocacy organisations, and people with disability and their families and carers to discuss this important issue.

Shortly after the release of the Public Advocate's report, a Joint Solutions Roundtable was convened by the Young People in Nursing Homes National Alliance. This took place in early December 2013. A further Joint Solutions Forum was held in February 2014. Both forums were convened to inform and discuss the call for a Joint Action Plan in Queensland to address the issue of people with disability living in hospitals and long-stay health care facilities. The forum heard from people with disabilities living in these facilities; their families; government representatives working on the Joint Action Plan; as well as representatives from the National Disability Insurance Agency.

In August 2014 the Queensland Anti-Discrimination Commission and Queensland Advocacy Incorporated held a joint forum – ‘Renaissance: Now or ?? – Continuing the Deinstitutionalisation of People with a Disability’ where numerous commentators including academics, advocates, professionals and people with disability spoke about the effects of institutionalisation and the possibilities for change. The Public Advocate, herself, also spoke at this forum.

At a local level, coordinated groups of government and non-government organisations are working together in some areas to advance the deinstitutionalisation. For example in the Metro North Health District in Brisbane, a Local Strategic Group has been formed to support the local level coordination needed to carry out the Queensland Government’s joint action plan. This group aims to improve pathways for long-stay residents of health facilities to community living.

In Toowoomba, one of the oldest long-stay health facilities for people with disability, Baillie Henderson Hospital, is in the process of developing a project plan and has commenced to establish a local network group to progress the necessary transition activities for residents still living on campus. This will include undertaking assessments, exploring alternate service models and developing sector capability.

These are just some of the activities that are occurring. The Public Advocate is pleased with the leadership of community groups in pursuing the engagement of government in response to this important issue.

### **The Public Advocate’s ongoing concerns**

These are important first steps, but the Public Advocate remains concerned about the process of deinstitutionalisation in Queensland. In particular, the Public Advocate is concerned about the lack of transparency in the process and the possible failure to learn lessons from past deinstitutionalisation processes including the need to be careful not to relocate people with disability to ‘new institutions’ in the community.

For example the ‘Joint Action Plan’ developed following the Public Advocate’s report by the then Queensland government was not publicly released. This means that neither the Public Advocate nor other community stakeholders or people with disability, their families and support people have had the opportunity to provide feedback or comment.

In December 2013, DCCSDS released expressions of interest for community organisation to tender for the *Provision of Accessible and Sustainable Accommodation for People with Disability in Residential Aged Care or Public Health Facilities*. This initiative, involving the allocation of \$6.6 million over two years is targeted at adults aged between 18 and 65 years who have a disability and are residing in, or at risk of entry into, residential aged care or who are long-stay in public health facilities. One-off capital grants will be available for the modification of existing dwellings or construction of accessible and sustainable accommodation for people with disability with high and complex support needs who are unable to have their needs met through other housing options such as social housing, community housing or public housing.

The allocation of these extra resources focused on transitioning people with disability in institutional environments into community living is welcomed. However this process must take place in accordance with the principles described above. The Expression of Interest states that “[i]n terms of accommodation design, preference will be given to either two or three people sharing in one dwelling. This will enable the sharing of support at key times and as needed.”<sup>29</sup>

There is a danger of the focus continuing to be on convenience, enabling efficient provision of support to people with complex needs in ready-built congregate environments, rather than embracing a person-centred approach where there is a focus on matching purposively designed support and accommodation options to the needs and preferences of individuals.

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<sup>29</sup> [www.communities.qld.gov.au/resources/funding/funding-available/apirac-funding-info-paper.doc](http://www.communities.qld.gov.au/resources/funding/funding-available/apirac-funding-info-paper.doc)

## Concluding comments

I commend the Committee for its inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Ensuring appropriate residential care and support arrangements for young people is an issue requiring immediate attention, particularly as we move forward under the National Disability Insurance Scheme.

It is an issue that extends across multiple human service systems, and will require a cohesive, integrated and outcomes-focussed approach to ensure meaningful and sustainable change.

Doing so will not only further Australia's ability to meet its obligations under the *Convention on the Rights of Persons with Disabilities* but will also accord young people the respect and dignity of living a life in which they are supported to access opportunities akin to those of their non-disabled peers.

While my submission has not focussed specifically on young people accessing support through the aged care system, the issues that I have raised in my submission are equally relevant to all young people with severe physical, mental or intellectual disabilities, regardless of the residential setting in which they access support.

I trust that this inquiry will lead to an improved understanding across government and the respective service sectors about the care and support needs of young people with severe physical, mental or intellectual disabilities, and to advancements in the social inclusion of young people.

I am pleased to lend my support to the Committee as it progresses this important inquiry in the interests of ensuring that future models of care meet the needs of the people they are designed to support. I would be pleased to make myself available to the Committee should there be an opportunity to expand on the points made in this submission.



**Jodie Cook**

**Public Advocate (Queensland)**

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