

Office of the Public Advocate

People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation

A systemic advocacy report

October 2013



Queensland
Government

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Foreword

Imagine your whole day being under someone else's direction and control; imagine never being given the opportunity to decide where you will live, the people you will live with, what you will eat, the book you will be read, the TV program you will watch; imagine being put to bed at 6:30pm every evening, even if you aren't tired; imagine spending your whole life sleeping in a hospital bed...

Now imagine having experienced an accident that results in you being in hospital for acute care and rehabilitation... the day comes when you have made all the gains possible in hospital and you are ready to be discharged only to find that you are forced to remain in hospital because there are no slow-stream rehabilitation beds available, and/or you are unable to get a house or the support that you need to continue your rehabilitation in a community setting...

For some Queenslanders, these situations are not something of the imagination but are instead a reality they have lived with for many years with no opportunity for change and no hope for the future.

In Queensland, many (but not all) institutions have now closed and there has been a concurrent increase in community-based arrangements. However, there are still many people with disability living in 'institutional type' settings, segregated from the community.

While we all know that the resources that are available to support people with disability are limited, few people have a full awareness of the extent to which many Queenslanders with disability live in sub-standard conditions with little or no ability to make decisions about their everyday lives.

The systems that are available to support people with disability in Queensland are fragmented, inequitable and under-resourced. I think we are mistaken to believe that the National Disability Insurance Scheme (NDIS) will resolve this issue.

The NDIS is, to some extent, premised on an assumption that the complementary systems that enable people with disability to be supported in the community are operating optimally. Given the number of people identified in the course of this project who remain living in institutional settings due to limited resources and/or relevant and necessary reforms in these complementary systems, this is clearly not an accurate assumption.

Furthermore, according to the Heads of Agreement between the Queensland and Australian Governments for the NDIS, the full roll-out of the Scheme will not occur before the end of this decade. This is too long for those people with disability who are restricted to hospitals, mental health facilities and other similar health services to have to wait.

Like the majority of us in the community, people with disability, including those with intellectual disability or cognitive impairment, need services and supports from a range of areas including health care, housing, specialist disability support, education and training. Many of these will not be provided by the NDIS.

There is an immediate need to ensure the crucial infrastructure to support a successful transition to the NDIS. The NDIS emphasises social and economic participation, which will necessarily require engagement with and support from not only the federal government but also relevant state government departments, local governments, private industry and the

community sector. Planning for the development and improvement of service pathways and necessary infrastructure, such as appropriate accommodation, must commence now.

It is neither acceptable nor appropriate for people with intellectual or cognitive disability 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, when the same person could be receiving more appropriate support in a community-based setting at a significantly reduced cost.

When touring the facilities and meeting with residents, 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 the state of Queensland. Without a commitment to change for people with disability residing in health facilities, without key government departments like health, disability services and housing working together, and without an end to the fragmented funding and resourcing approach, we are unlikely to see any significant change, even with the transition to NDIS.

Many of the submissions I received called for increased Government collaboration, for key Departments to work across their portfolios to facilitate a planned response. After all, given the range of services that people with disability need, ensuring an equitable response to people with disability should not, and clearly cannot, be the responsibility of one department. I believe that with proper collaboration and commitment those people with disability currently living in health facilities can be supported to achieve immediate and significant improvements in their lives.

However, while systems change is required to enable this, we must be mindful to ensure that people with intellectual disability or cognitive impairment who are residing in long-stay health care facilities are recognised as individuals, with planning taking place on a person-by-person basis.

During the course of this project I have been pleased to see commitment to change and examples of good practice emerging. The Department of Health and the Department of Communities, Child Safety and Disability Services collaborated to table a joint submission indicating a number of short- to medium-term initiatives they will undertake to address this issue. I have also seen local level improvements with new models focused on goal-centred rehabilitation in slow-stream rehabilitation services such as Casuarina Rehabilitation Centre and Jacana Acquired Brain Injury Service.

I thank all those who took the time to make a submission on this important issue and/or meet with me to convey their views. I also thank the staff and residents of the long-stay health facilities who made time to discuss this issue and provided the opportunity to see the various facilities first-hand.

As Public Advocate, I urge the Queensland Government not to ignore this group of vulnerable Queenslanders and to act now to improve their opportunities for the future. It is neither equitable nor acceptable for some people with intellectual or cognitive disability to continue living in hospitals whilst others are supported to lead fulsome lives and reach their potential living in the community.



Jodie Cook
Public Advocate

Executive summary

Background

In June 2013, the Office of the Public Advocate commenced a research and advocacy project focused on continuing the deinstitutionalisation of people with disability in Queensland. The focus of this report reflects the initial stage of this project, which considered people with intellectual disability or cognitive impairment who reside in long-stay health care facilities.

On 17 June 2013, the Public Advocate released a Position Statement (on continuing the deinstitutionalisation of people with disability in Queensland, Appendix 2), a Project Fact Sheet (Appendix 3) and a Call for Submissions (Appendix 4).

Information was also sought from the Department of Health about the number of people who continue to reside in long-stay health care facilities, and a response sought from both the Department of Health and the Department of Communities, Child Safety and Disability Services about the extent to which they are working together to plan for more appropriate community-based accommodation and support services for these individuals.

The Office of the Public Advocate received 21 submissions from interested parties, including family members of people with disability residing in institutional settings, community organisations, advocacy organisations, staff of health facilities and a joint submission from the Department of Health and the Department of Communities, Child Safety and Disability Services. These submissions are listed at Appendix 1 although some submissions, either where requested or where they may identify a resident of a facility, are confidential and their authors cannot be identified.

The Department of Health provided three sets of data. First, information was provided about the numbers and demographic profile of people with intellectual disability or cognitive impairment residing in mental health services in Queensland. This data had been collated by the Department of Health in May 2013. Second, aggregated data was provided in relation to the number of people with intellectual disability or cognitive impairment residing in Queensland Hospital and Health Services. This data was collated by the Department of Health in July 2013. Finally, data was provided as part of the joint submission by the Department of Health and the Department of Communities, Child Safety and Disability Services. The data provided to inform this project is described in Part 2 of this report.

The Public Advocate and staff from the Office met with various stakeholders, visited a number of health facilities and spoke with staff and residents of facilities. These meetings and visits are also listed at Appendix 1.

Summary of findings

Institutionalisation of people with disability in Queensland

The history of institutionalising people with intellectual disability in Queensland is similar to the history of institutionalisation of people with intellectual disability in many other western and developing countries, including the United States and the United Kingdom.

Up until the 1980s in Australia, it was common practice for people with disability to reside in large institutions on the outskirts of cities. These institutions housed both children and adults with disability in congregate living environments, with all day-to-day decisions made on their behalf by staff.

Originally people with intellectual disability in Queensland were placed in asylums and described as 'lunatics' or 'insane'. Early 'reforms' in the 1960s saw the separation of many people with intellectual disability from people with mental illness and the development of training centres and other facilities specifically for people with intellectual disability.

Queensland, like other Australian states experienced significant closures of large institutions and the relocation of people with disability to community-based living in the 1980s and 1990s. This coincided with increases in community-based accommodation provided by government and non-government services. This movement was also given impetus by investigations into cultures of abuse and neglect of people with disability in some of these facilities.

People with disability remaining in institutional environments

At some point however these 'reforms' were stalled and a significant number of people with intellectual disability or cognitive impairment remain living in long-stay health care facilities in Queensland.

As at May 2013, there were 271 people with intellectual disability or cognitive impairment who continue to reside in long-stay health facilities in Queensland. This included 131 people with intellectual disability or cognitive impairment who were 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 residing in state-funded and operated aged care facilities; and 30 people residing in various hospitals and other health services. A further 98 people with intellectual disability reside in authorised mental health service facilities in Queensland.

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 the community. Some residents have lived in these facilities up to 35 years.

Submissions to the Public Advocate confirmed that, despite the best intentions of staff, in many cases the models of care provided in health facilities where people with intellectual disability or cognitive impairment reside do not meet contemporary standards for people with intellectual disability or cognitive impairment. In particular, support is not provided to develop the functional skills and capability of people with disability. Neither do they receive

adequate support to ensure the best outcomes regarding their physical, social and emotional well being. Furthermore, there are few opportunities provided for choice or participation in the community.

Many people in these facilities sleep in hospital beds in 'ward like' environments, some have done so for up to 65 years, despite these places being described as their 'homes' and recognition that these arrangements are not required for 'medical care'. The facilities are often noisy with little privacy. They are staffed by nursing and other health staff, and a medical model of care predominates. The low staff-to-resident ratio means that most of the day is taken up with personal care with few opportunities for personal support or to learn activities of daily living. Most things are done 'to them' or 'for them'. The size and nature of the facilities mean that there are rigid routines, for example strict 'bed times', regardless of a person's age or desires they may have for a routine that suits their personal needs or wishes. Access to the community is limited and for some non-existent.

It was submitted to the Public Advocate that, under these conditions, 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.

A family member of a resident in a long-stay health care facility stated:

"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. Sophie has also been denied the right to a good education and work opportunities, and the right to develop healthy relationships. Instead she has lived a wasted life with a lack of purpose, loneliness and isolation, in a segregated environment filled with a medical routine."¹

In the 2012-13 financial year, it cost the Queensland Government approximately \$76.28 million to support people with disability who are residing in health care facilities. The Public Advocate contends that at least some of these funds could be reallocated to provide people with disability living in health care facilities with more appropriate models of care and support in the community.

People with intellectual disability in long-stay health care facilities

There are a number of people with intellectual disability or cognitive impairment residing in institutional settings that were originally built as long-stay health care facilities, including Baillie Henderson Hospital and the Halwyn Centre.

For example, there are currently 26 residents with intellectual disability or acquired brain injury who remain in Baillie Henderson Hospital. These residents range in age from 36 to 64 years, and have varying length of stays extending from 10 up to 65 years. There are also 44

* The resident's real name has not been used.

¹ Confidential, Submission No 7 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

people with intellectual disability residing in Halwyn Centre at Red Hill. These residents range in age from 22 to 63 years with varying lengths of stay from 5 up to 35 years.

These facilities are administered and operated by the Department of Health, and are segregated from the community. Although, arguably, the people in these facilities are provided with good 'medical care', they do not receive the support they need to develop their capabilities and reach their full potential.

It was submitted to the Public Advocate, in relation to the group of residents at Baillie Henderson Hospital, that:

"an assessment by Dr Michael Kendrick in 2010 supported the intent that it would be possible and would be beneficial from a care and quality of life perspective, to relocate some of these people to community accommodation but this would require whole of government commitment and dedicated resources to facilitate a systems response and at the same time guarantee a robust response at an individual level. If this were to happen it would go a long way to meeting our obligations from a human rights perspective and the United Nations Conventions."²

People with acquired brain injury in long-stay health care facilities

The response to people with ABI in Queensland is characterised by a 'bed blocked' system with a 'ripple effect' of subsequent consequences both economically for the state and personally for individuals who do not get access to the crucial rehabilitation they need following a catastrophic injury.

Many places that were intended as slow-stream rehabilitation services have unfortunately become long-term destinations with many people residing in these services for 15 to 20 years. This prevents these facilities from operating as short-term rehabilitation services, services that are sorely needed in Queensland.

Many people with ABI now 'live' in facilities that were meant for intensive short-term rehabilitation with others residing in acute hospital beds and mental health services. The bed blockages in the rehabilitation services (or downstream blockages) mean that pressure starts to build up in acute hospitals to the extent that the next wave of people with ABI have nowhere to go once the acute phase of their care has passed. This creates a situation where many people with ABI are discharged from hospital into the care of their families without appropriate rehabilitation or support. They may also be discharged into aged care facilities.

A by-product of not receiving appropriate rehabilitation support and/or being discharged to inappropriate environments is the potential for readmission to acute care facilities, or institutionalised models of support being implemented to address the gap between a person's needs and the available levels of care.

These bed blockages have serious impacts, both economically for the public health system and for the long-term recovery and rehabilitation of individuals with ABI. It was submitted that:

² D Rogers and S Wigan, Submission No 15 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 8 August 2013, 3.

The cost to the public health system of keeping someone in a hospital bed for 412 days after their medical needs were stabilised waiting for available funds to transition them to the community was \$325,000 more than what it would have cost for the same person to live in the community with access to support and therapy.³

Further, people who remain in institutional environments for long periods of time experience significant deterioration in their health and wellbeing, and can also lose important life skills, including continence and mobility skills, that may have initially been regained in hospital-based rehabilitation. The loss of these skills not only limits community discharge options but can lead to further time in, or readmission to, acute care. In other words, the longer a person stays in an institutional environment, the more complex and costly they become to support in the community and the likelihood of them attaining the optimal levels of independence rapidly diminishes.

Indigenous people with disability in long-stay health care facilities

The Public Advocate received anecdotal reports suggesting that there is a lack of adequate data in relation to Indigenous people, both quantitatively with respect to the numbers residing in long-stay health care facilities and qualitatively on their experience in these facilities.

If substantiated, these gaps are likely to limit the ability of relevant Departments to generate culturally appropriate strategies for transition back to community-based living.

The data provided by the Department of Health indicated that, state-wide, there were fewer than five Aboriginal and Torres Strait Islander ‘patients’ who had been residing for long periods of time in hospital settings (exclusive of mental health facilities). However stakeholders and key informants who work with Indigenous people have indicated that this is unlikely to be an accurate figure.

It is an acknowledged limitation of this report that there is little information on which to base a comprehensive picture of the numbers of, and issues for, Indigenous people with disability living in long-stay health care facilities.

The Public Advocate has committed to working more closely with key government departments and non-government agencies, including those agencies that form part of the guardianship system, to advocate for the better collection of data in relation to Indigenous people with impaired decision-making capacity and to better understand the issues for Aboriginal and Torres Strait Islander people with intellectual disability or cognitive impairment in the current service system in Queensland.

Core principles and summary of recommendations

The Public Advocate strongly recommends that the Queensland Government make a whole-of-government commitment to improving care and support for people with intellectual disability or cognitive impairment residing long-term in health care facilities, and ensures

³ Quarterly Brain Injury Services Meeting (QBISM) Group, *A Comprehensive Service System for Queenslanders with Brain Injury, Positioning Paper* (August 2013) 19.

that this commitment is funded, prioritised, participatory, individualised and coordinated to enable appropriate opportunities for social inclusion and community participation for these vulnerable Queenslanders. These core principles are summarised below and further detailed in Part 7 of this Report.

Core principles

Funded

Improving the response to people with disability who currently reside in long-stay health care facilities cannot be done without additional investment and/or a reallocation of existing resources. The Queensland Government must move away from the current fragmented approach and address this as a whole-of-government issue.

Prioritised

Historically, the low priority accorded to these individuals has been informed by a view that they are currently living in stable accommodation where their care needs are being met. Given that this group of people are currently in inappropriate accommodation, not receiving support services congruent with Australia's international human rights obligations, and at significant risk of deterioration in their health and well being, the Public Advocate contends that these factors should be accorded the highest level of priority.

Participatory

The person themselves must be actively involved in assessment and transition planning. Information must be provided in accessible formats and people must be supported in their decision-making with respect to options for the future. Family members must also be engaged, kept informed and involved, have the opportunity to voice their perspectives and concerns and be able to provide input into assessment and planning.

Individualised

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 standards of providing funded support to people with disability and the standard that will be upheld through the National Disability Insurance Scheme. Individualised assessments must be cognisant of cultural issues, with particular recognition for Aboriginal and Torres Strait Islander people with disability residing in long-stay health care facilities.

Coordinated

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 health, housing and disability services. The development of policy, protocols and/or memorandums of understanding must provide authority for local-level approval to prioritise and allocate resources to individuals, and to coordinate the delivery of services, accommodation and clinical support.

Summary of recommendations

- There should be an immediate start to the provision of thorough individual assessments by senior clinical staff of the support needs of the entire group of people, with priority given to people who do not have a current assessment (for example those residing in Baillie Henderson Hospital and Halwyn Centre). These assessments should also consider the extent to which a person's support needs could be better met in a community setting.
- There needs to be a change to the fragmented way in which resources are allocated across existing portfolios to support these individuals, including a reallocation of existing resources currently used to care for people in health care facilities to support more appropriate models of care and support.
- An Action Plan must be developed and implemented to support the transition of people with disability in these environments to appropriate models of support and/or alternate accommodation in the community as soon as possible.
- Local level coordination should be encouraged, formalised and supported by commitment from the highest levels of the relevant departments to enable authorised and prioritised coordination of services to this group.
- The Queensland Government should make further investment in identifying and/or developing a range of appropriate accommodation options to enable people with intellectual disability or cognitive impairment currently residing in health facilities to transition to the community where appropriate and desired.
- There must be further investment in a range of rehabilitation services for people with acquired brain injury, including community-based rehabilitation. This should not be limited to facility-based rehabilitation but should also be accessible to people living in the community.
- A coordinated approach for people with acquired brain injury must be developed to improve pathways and access to the current service system.
- There must be improvements in the collection of quantitative data and qualitative information on Indigenous people with intellectual disability or cognitive impairment residing in long-stay health care facilities to inform culturally appropriate alternatives to hospital admissions and to increase the success of opportunities for transition back to community living.
- The needs of this group of people must be considered in the phased approach to the National Disability Insurance Scheme.

Overview of this report

This Report provides a summary of the information and evidence gathered and key recommendations for change.

Part 1 provides a short history of the institutionalisation of people with disability in Queensland. This also includes a history of reforms that have occurred over the past few decades [Page 1]

Part 2 provides an account of the number of people with intellectual disability or cognitive impairment who continue to reside in long-stay health care facilities in Queensland, including the numbers of people in each key health facility, their median ages and length of stay in the facility [Page 13]

Part 3 provides an overview of why supporting people with disability in institutional environments is not consistent with modern standards of care and support, nor human rights obligations [Page 19]

Part 4 provides further information about people with intellectual disability in long-stay health care facilities and their future needs [Page 27]

Part 5 provides further information about people with acquired brain injury in long-stay health care facilities and their future needs [Page 40]

Part 6 provides an outline of what actions are currently being taken by the Queensland Government to address this issue [Page 55]

Part 7 provides an outline of what the Public Advocate believes is required to adequately and properly respond to this group of people, including the key recommendations of this report [Page 60]

Conclusion [Page 69]

Bibliography [Page 71]

Appendix 1 provides a list of submissions to the Public Advocate in response to the call for submissions on People with Disability in Long-Stay Health Care Facilities [Page 75]

Appendix 2 presents the Position Statement released by the Public Advocate in June 2013 [Page 77]

Appendix 3 presents the Project Fact Sheet that was published by the Public Advocate in June 2013 [Page 79]

Appendix 4 presents the Call for Submissions that was issued by the Public Advocate in June 2013 [Page 81]

Terms

Term	Definition
Acquired Brain Injury (ABI)	An acquired brain injury refers to the multiple disabilities arising from damage to the brain that occur after birth. Damage to the brain may be caused by an accident or trauma, by a stroke, a brain infection, by alcohol or drugs, or diseases of the brain such as Huntington's disease.
Cognitive impairment	A cognitive impairment describes a loss of brain function affecting judgment, resulting in decreased ability to process, learn and remember information. It can manifest itself in a variety of conditions including Alzheimer's disease, dementia, autism and autism spectrum disorders, multiple sclerosis, and acquired brain injury.
Forensic order	A forensic order can be made by the Mental Health Court when a person who has committed an indictable offence (or an indictable offence and another simple offence) is found to be of unsound of mind or unfit for trial. A forensic order can detain a person to an authorised mental health service or the Forensic Disability Service. Once detained to that service, limited community treatment may be approved that allows the person to access the community.
Intellectual disability	An intellectual disability exists where there is significant limitation in intellectual functioning and adaptive behaviours such as conceptual skills, social skills and functional skills, and where this becomes apparent prior to 18 years old.
Long-stay health care facility	For the purposes of this report, long-stay health care facilities refer to any place operated by the Department of Health in Queensland where a person with disability has been residing past the time when their medical needs have been stabilised. In this report, these facilities include places originally built for people with disability to reside (such as Halwyn Centre and Baillie Henderson Hospital); mental health services; state government-operated aged care services; and hospitals and other health care services.
National Disability Insurance Scheme (NDIS)	The National Disability Insurance Scheme (NDIS) is a scheme for providing lifetime care and support for people with permanent impairment who meet the eligibility requirements with the aim of assisting them 'to realise their potential for physical, social, emotional and intellectual development' and 'participate in social and economic life'. It was designed and recommended by the Productivity Commission as a result of its nationwide inquiry into disability care and support. The implementation of the NDIS was supported by the Council of Australian Governments in 2011.

Term	Definition
National Disability Insurance Scheme (NDIS) (continued)	The NDIS is currently administered by the National Disability Insurance Agency, an independent statutory agency whose role it is to implement the NDIS. The scheme commenced in July 2013 and is being introduced in stages. It is expected that all eligible Queenslanders will be covered by July 2019.
Public Advocate	The Public Advocate is a statutory position that is given authority by the <i>Guardianship and Administration Act 2000</i> . The role of the Public Advocate is to promote and protect the rights of adults with impaired decision-making capacity through engaging in systems advocacy. Systems advocacy involves identifying serious problems impacting a group of people with impaired capacity, and influencing legislative, policy and/or process change to resolve the issue.

Part 1: History of institutionalisation in Queensland

Introduction

This part provides a short history of the institutionalisation of people with intellectual disability or cognitive impairment in Queensland, including a history of the reforms that have occurred over the past few decades.

Institutionalisation

Up until the 1980s in Australia, it was common for people with disability to reside in large institutions on the outskirts of cities. These institutions housed both children and adults with disability in congregate living environments offering little or no opportunity for self-determination, and all day-to-day decisions were made by staff of the institution on their behalf.

People with intellectual disability were initially detained with people who were mentally ill or criminals. From the mid to late 19th century in Australia, people with intellectual disability were placed in jails or asylums for the mentally ill and described as 'lunatics' or 'insane'.⁴ This co-location of people with intellectual disability with people with mental illness occurred as a common practice until the mid-20th century when residential centres, training centres and institutions were developed specifically for people with intellectual disability. There was also an increase in professional and specialist services for people with intellectual disability.

These changes, including the increased institutionalisation of people with intellectual disability, corresponded with immense social and economic changes in western and developing countries, which in many cases, led to reduced capacity for families to care for people with intellectual disability or mental illness at home.⁵ Families had two options: either care for their family member at home with no support, or place them in institutions. There was significant pressure and expectation on families to place their family members with intellectual disability in institutions.

Conditions in institutions

Institutional settings were custodial in nature. They provided all services within the institution, rather than allowing people with an intellectual disability to venture into the community. In these settings people with intellectual disability had few rights, were subject to containment in hospitals and asylums under the authorisation of medical practitioners with no opportunities

⁴ T Carney and P Singer, *Ethical and Legal Issues in Guardianship: Options for Intellectually Disadvantaged People* (Watson Ferguson and Co, 1986).

⁵ 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, 2001); 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). These changes included increased mobility, smaller families and rapidly expanding poverty in urban areas.

for review, and personal decisions about treatment, life style and education were made by the staff of the institution. They were under the complete control and direction of the institutional staff and government. Medical treatment could be carried out without consent.

Eileen Thomson describes the conditions at what is now known as the Baillie Henderson Hospital (Toowoomba) during the inter-war years.

“The custodial care was restrictive to many patients and staff and not unlike military discipline, and yet it was tempered by sympathetic care especially for the young, sick and elderly. Overcrowding and difficulties with classifying patients in the large wards made treatment difficult. Staff worked long shifts e.g. 6.00a.m. to 6.00p.m. During the day, staff members spent two hours at a time in yards with a variety of unpredictable patients, some of whom were aggressive enough to require physical restraint. [...] At night most patients slept in dormitories where there were rows of beds. Violent patients had single cell-like rooms with wooden shutters.”⁶

Further to this, are the recollections of an official visitor to what was to become Challinor Centre, 1966.

“On my initial visit, I found an institution used mainly as a place for keeping certain people out of circulation. Remedial treatment and turnover were practically nil. Patients were eking out a 24 hour daily existence in impoverished conditions and some practically in squalor. Many requests for discharge were ignored and not worth recording. Paramedics were unknown. I could have been forgiven had I returned to the gate to see if I had missed a caption reading, ‘Abandon hope all ye who enter here.’”⁷

Queensland’s history of institutionalisation

Historically in Queensland, like many other places, there was little or no distinction between the care for people with intellectual disability and that provided for people with mental illness. In Queensland, a number of large government institutions for people with mental illness and intellectual disability were built on the outskirts of Brisbane, Ipswich and Toowoomba. People with intellectual disability were housed with people with mental illness in the Ipswich Special Hospital, Woogaroo Lunatic Asylum (Wacol, Brisbane) and the Baillie Henderson Hospital (Toowoomba) under the control of the Health Department.

While the Department of Education made some provision for children with intellectual disability through the ‘opportunity school’ system, children were mostly seen as a Health Department responsibility. The 1952 and 1953 Department of Education reports that recommended the formation of these schools also recommended that children with IQs below 60 should not be admitted and that the Director-General of Health and Medical Services should accept responsibility for these children under the *Backward Person’s Act 1938*.⁸

⁶ E Thomson, *Baillie Henderson Hospital Toowoomba: A Century of Care* (1990) 21.

⁷ E McRobert, *Challinor Centre: The End of the Line: A History of the Institution also known as Sandy Gallop* (Department of Families, Youth and Community Care, Brisbane Queensland, 1997) 112, quoted in University of Queensland, *Ipswich Campus: Progression of an Institution*, University of Queensland: Ipswich Library Online Exhibition <<http://www.library.uq.edu.au/ipswich/uqihistory/>>.

⁸ Ministerial Taskforce on Services for People with an Intellectual Handicap, *A Place for Everyone: Report to the Ministerial Taskforce on Services for People with an Intellectual Handicap in Queensland* (Chaired by Beryce Nelson, 1989) 23.

From the mid-1960s, some residential services for people with intellectual disability began to be segregated from people with mental illness. This began with the decision by Cabinet in 1966 to designate the Ipswich Special Hospital as a training centre for ‘intellectually handicapped’ adults and rename it as the Challinor Centre. The section of Wolston Park Hospital that accommodated ‘intellectual handicapped children’ was designated as the Basil Stafford Training Centre.⁹

In 1967 the below statement was read in the Queensland Legislative Assembly in relation to supporting people with disability separately to people with mental illness.

“Because the traditional attitude has been for the mental hospital to provide an asylum for the rejected patient, and because hospitals had been regarded as the end of the road for difficult nursing and social problems, the intellectually handicapped not supported by relatives or friends gravitated towards them, in the same way as senile people not supported by their families also gravitated towards them. This situation is no longer acceptable, and the Government has initiated a policy directed towards the provision of specific institutions for the care of these patients. This is based on the view that the intellectually handicapped are not necessarily mentally ill. As a group, they can be classed with those who suffer physical handicaps. Furthermore, this movement towards specific institutions is firmly based on the fact that these handicapped persons require training and care quite distinct from that necessary for the mentally ill.”¹⁰

While some people with intellectual disability began residing separately from people with mental illness in specific facilities for people with intellectual disability, these places were still institutional in character, housing large numbers of people with intellectual disability in hospital-like environments.

Queensland’s state-run institutions

Challinor Centre

The Ipswich Special Hospital was established as a psychiatric hospital on the outskirts of Ipswich in 1878. In 1968, it changed its name to the Challinor Centre with its purpose being the provision of services to people with intellectual disability. In the mid-1970s, the Challinor Centre had approximately 530 residents, but by 1995 the population had declined to 160 as residents started to be relocated from the centre. The relocation of all residents was completed in October 1998.¹¹

⁹ Ibid.

¹⁰ S D Tooth, Member for Ashgrove, Minister for Health, *Parliamentary Debates*, Legislative Assembly, 9 November 1967.

¹¹ L Young, A Ashman and P Grevel, ‘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.

Basil Stafford Centre

The Wolston Park Special Hospital at Wacol was founded as a 'lunatic asylum' in 1865 (the Woogaroo Lunatic Asylum), opening with 69 patients. For nearly a century, residential care services of a custodial nature were provided to people with both mental illness and intellectual disability. In the 1880s, the name was changed to the Goodna Lunatic Asylum and then later to the Goodna Hospital for the Insane, with steady growth in the number of residents.

The population peaked in the mid-1950s, with approximately 2500 residents and 700 staff. In the mid-1960s, a separate Children's Centre for children with intellectual disability was established providing hospital-style accommodation, and in 1968 the facility was renamed the Basil Stafford Centre. In 1995, there were still 122 persons residing at the centre, 17 of whom were children.¹²

The site of the Basil Stafford Centre at Wacol continues to house people with disability in institutional-type environments.

Baillie Henderson Hospital

The Baillie Henderson Hospital is situated in Toowoomba. It was initially established as Toowoomba Mental Hospital, an 'outstation' of the Woogaroo Lunatic Asylum at Wacol, which could not keep pace with the admissions for the entire state.¹³

Baillie Henderson Hospital opened in 1890 and by 1891, 83 men and 124 women were admitted, mostly from Woogaroo. By 1927, there were 598 men and 581 females, including people with mental illness, children with intellectual disability, people with epilepsy, and people with alcohol addiction.¹⁴

¹² Criminal Justice Commission, *Report of an Inquiry Conducted by the Honourable DG Stewart into Allegations of Official Misconduct at the Basil Stafford Centre* (March 1995), tabled in Parliament 11 April 1995; W Carter, *Challenging Behaviour and Disability: A Targeted Response* (2006) 23.

¹³ Thomson, above n 6, 6.

¹⁴ Ibid 21.

Deinstitutionalisation in Australia and Queensland

The movement of people with intellectual disability from large-scale residential facilities to community-based living, known as deinstitutionalisation, began in the 1960s and 1970s in most western and developing countries and is recognised as one of the most significant changes in human services to occur in the 20th century.¹⁵

In Australia, deinstitutionalisation began much later, in the 1980s, and progressed at a slower rate in comparison to the United States, United Kingdom and some parts of Europe.¹⁶ Nevertheless, there were significant reductions in the numbers of people with intellectual disability living in institutional environments, particularly in the 1990s. In 1988, it was estimated that there were 7,500 people with intellectual disability residing in large state or private residential centres or psychiatric hospitals throughout Australia.¹⁷ By 1999, this number had reduced to 4,340 people with intellectual disability living in institutional accommodation.¹⁸

Throughout the 1970s the tensions associated with providing services for people with intellectual disability within the psychiatric services structure began to be realised. In 1976 a Health Paper, *The Care of the Intellectually Handicapped* was tabled by the Queensland Minister for Health¹⁹ outlining a new model of residential care for people with intellectual disability based on education and training, the creation of new caring professions to implement the model, the building of small community residential villas and a policy of 'normalisation'.²⁰

The following statement was read by the Honourable L.R. Edwards MP to accompany the release of the Health Paper, *The Care of the Intellectually Handicapped*, 1967

"New initiatives in the management of the intellectually handicapped in Queensland will ensure a new deal for these people within the community. The new plans, including the development of a new caring profession to specially train the intellectually handicapped have been fully documented in a Health Department paper. This paper outlines the Government programmes, including the development of the villa schemes and we have already embarked upon the programme of community supervised hostels. [...] This new policy of care for the intellectually handicapped will mean that many more of these folk will take their place within the community and live together with normal people."²¹

In 1977 the Intellectual Handicapped Services branch was created within the Health Department to implement the Health Paper.

¹⁵ Young, Ashman and Grevell, above n 11, 52.

¹⁶ L Young et al, 'De-Institutionalisation of Persons with Intellectual Disabilities: A Review of Australian Studies' (1998) 23(2) *Journal of Intellectual and Developmental Disability* 155.

¹⁷ L Bostock et al, *De-Institutionalisation and Housing Futures: Final Report* (Australian Housing and Urban Research Institute, 2001) 14-15.

¹⁸ Ibid.

¹⁹ Health Department (Queensland), *Health Paper: Care of the Intellectually Handicapped* (1976), tabled in the Legislative Assembly, 9 March 1976 by the Honourable L.R. Edwards, Minister for Health.

²⁰ Ministerial Taskforce on Services for People with an Intellectual Handicap, above n 8, 23-4. The principles of normalisation are described in Part 3 of this Report.

²¹ L R Edwards, Member for Ipswich, Minister for Health, *Parliamentary Debates*, Legislative Assembly, 9 March 1976.

These policy changes and accompanying closures of several institutions also coincided with the development of new services and accommodation modalities for people with disability in Queensland, including the Alternative Living Service and more recently Accommodation Support and Respite Service (AS&RS), which saw many people from institutions transition to community living in the 1990s.

A number of non-government services were also established, many through the efforts of parents and friends of people with intellectual disability, in response to the gap in government services. This transition to further community-based living also saw a growth in government-funded community organisations, which have delivered accommodation and related services to persons with intellectual disability in receipt of funding from disability services.²²

In 1982, the *Parliamentary White Paper on Services for Intellectually Handicapped People in Queensland: A view for the Eighties and Beyond*, was tabled by the Minister for Health. This paper reinforced the commitment of the newly formed Intellectual Handicapped Services branch to the principles of normalisation and the least restrictive alternative and set out the organisation structure, goals and objectives of the service.²³

Over the following years until 1984, some 140 people from Wolston Park Hospital were transferred to facilities operated by the Intellectual Handicapped Services branch.²⁴ In 1987, administrative responsibility for the Intellectual Handicapped Services branch moved from the Department of Health to the Department of Family Services.

In July 1989 the Ministerial Taskforce on Services for People with an Intellectual Handicap in Queensland Report, *A Place for Everyone*,²⁵ was tabled in the Legislative Assembly. The Report focused on a proposal for community services provisions and development for people with an 'intellectual handicap' and recommended the need to develop a range of models for residential services consistent with the principles of the report²⁶ as well as the urgent need for a review of staffing arrangements in residential services to ensure a flexible service that meets clients needs was provided.²⁷

Continuing the deinstitutionalisation process

Specifically as part of the 1989 Report's overall proposal for community services development, it recommended continuing the deinstitutionalisation process including the following specific references:

- **People with 'intellectual handicap' residing in psychiatric hospitals:** With a particular focus on the two large groups of people with intellectual disability that were residing at Baillie Henderson Hospital (Toowoomba) and Mossman Hall (Charters Towers), it was stated that:

²² Carter, above n 12, 124.

²³ Ministerial Taskforce on Services for People with an Intellectual Handicap, above n 8, 24. The principles of normalisation are described in Part 3 of this Report.

²⁴ Ibid 25.

²⁵ Ibid. Tabled in the Legislative Assembly 7 July 1989 by the Honourable Craig Arden Sherrin MP, Member for Mansfield, Minister for Family Services and Corrective Services.

²⁶ Ministerial Taskforce on Services for People with an Intellectual Handicap, above n 8, recommendation 21.

²⁷ Ibid, recommendation 23.

“Following the 1966 Cabinet Decision which specified that people with an intellectual handicap should be provided with services separately to people with a psychiatric illness, it is inappropriate that people with an intellectual handicap still be cared for in psychiatric hospitals.”²⁸

- **The Challinor Centre:** It was recommended that the large residential complex should be reduced to 185 people by 1990, with relocation of all residents to follow by late 1994.²⁹
- **The Basil Stafford Training Centre:** Progressive reduction of the number of people in this facility was recommended through until late 1992, at which point the majority of people should be living in community settings supported through an expansion of the Alternative Living Service.³⁰
- **Hospital Annexes:** It was proposed that there should be a reduction of the number of people in hospital annexes, particularly those in Maryborough and Rockhampton with relocation of people to community-based settings. It was proposed that Halwyn Centre be managed by the Intellectual Handicapped Services branch.³¹
- **No further admissions:** It was recommended that:

“...no further admissions should be made to large centralised residential centres and that accommodation needs should be met at a regional level unless the person with an intellectual handicap requires assistance that can only be provided in a setting where specialist skills and resources are available.”³²

Later, many of the large institutions were closed in Queensland. For example the Challinor Centre was closed in 1998. Its population of residents had declined from 530 in the mid-1970s to 160 in 1995, with the relocation of all residents completed in October 1998.³³

This corresponded with similar closures in other western and developing countries where positive outcomes for people with disability as a result of moving into the community were measured, including substantial improvements in daily living skills, more contact with family, improvements in communication and social skills,³⁴ greater social interaction, increased recreational and leisure activities and greater use of community facilities.³⁵

A study of 95 individuals who were relocated from the Challinor Centre found that after 12 months of community living they had achieved significant improvements in adaptive skills, especially self care, independent or semi-independent economic activity (such as shopping), domestic skills (such as laundry and cooking) as well as an improvement in general quality of life. The move to community also offered more opportunities to make choices and live a lifestyle similar to adults without disability.³⁶

²⁸ Ibid, 175.

²⁹ Ibid 176.

³⁰ Ibid.

³¹ Ibid 177.

³² Ibid 178.

³³ Young, Ashman and Grevell, above n 11, 53.

³⁴ L Chenoworth, ‘Closing the Doors: Insights and Reflections on De-Institutionalisation’ (2000) 17(2) *Law in Context* 77, 84; S Kim, S A Larson and C K Lakin, ‘Behavioural Outcomes of De-Institutionalisation for People with Intellectual Disability: A Review of US Studies Conducted Between 1980 and 1999’ (2001) 26(1) *Journal of Intellectual and Developmental Disability* 35.

³⁵ Young, et al, above n 16, 8.

³⁶ Young, Ashman and Grevell, above n 11, 63.

Evidence also suggests that some people who transitioned to community-based living did not achieve similar levels of success. The lessons learned from these situations are detailed further toward the end of this part of the Report.

Institutional culture, incidents of abuse, neglect and exploitation: Queensland's history

It should be noted, however, that not all institutional facilities were closed during this period of deinstitutionalisation in Queensland. For those that remained, in particular Baillie Henderson Hospital and the Basil Stafford Centre, a number of key investigations and inquiries uncovered patterns of neglect, abuse and exploitation in these settings.

A number of reports were tabled in the Queensland Parliament during the mid-1990s concerning institutional-type living environments for people with disability and findings of abuse and neglect, insidious institutional cultures, and inappropriate models of care. These included:

- *Report of an Inquiry Conducted by the Honourable D G Stewart into Allegations of Official Misconduct at the Basil Stafford Centre*, Tabled in Legislative Assembly 11 March 1995;
- *Report to the Minister for Health and the Parliament of Queensland on Investigations by the Health Rights Commissioner at Baillie Henderson Hospital, Toowoomba*, Tabled in Legislative Assembly 26 November 1996; and
- *A Review of the Basil Stafford Centre Recommendations: Report to Disability Services Queensland by the Honourable W J Carter QC*, Tabled in Legislative Assembly 1 June 2000.

D.G. Stewart's inquiry into Basil Stafford Centre

The Honourable D.G. Stewart was appointed by a resolution of the Criminal Justice Commission dated 10 December 1993 to conduct an inquiry into a number of allegations that had been received by the Commissioner regarding official misconduct occurring in the Basil Stafford Centre.

The Inquiry uncovered further evidence of abuse and concluded that between 1985 and 1993 a number of unlawful assaults had been perpetrated upon clients by staff at the Basil Stafford Centre and that "while a proportion of staff at the Centre were caring and committed in their endeavours, a not insignificant number of staff members were ignorant of their responsibilities, had an attitude of indifference, and in some cases were unwilling to act decently towards the intellectually disabled persons placed in their supposed care."³⁷

³⁷ Criminal Justice Commission, above n 12, xii.

D.G. Stewart's inquiry into Basil Stafford Centre (continued)

The inquiry into Basil Stafford Centre found: "an insidious institutional culture existed at the Centre" and this culture "promoted the occurrence of client abuse and gross neglect, and the harassment or intimidation of staff members who reported or could have reported such occurrences."³⁸

D.G. Stewart's primary recommendation was that the problems of the Centre were of such a nature that the only practicable solution was to close the Centre at the earliest possible opportunity.³⁹

Health Rights Commission (HRC) investigation into Baillie Henderson Hospital

In 1995, the Queensland Health Rights Commissioner received a complaint from a registered nurse at Baillie Henderson Hospital, which was followed by complaints by patients, their representatives, and members of nursing and support staff about services at Baillie Henderson Hospital. The allegations to the HRC indicated there was a culture of abuse of clients in many of the units of Baillie Henderson Hospital, with residents being treated in demeaning and humiliating ways.⁴⁰

On 26 November 1996, the HRC tabled the report of its investigation in the Queensland Parliament. The Report contained disturbing findings of abuse and neglect of patients, including patients with intellectual disability. The Commission's Report included comments about the conditions for over a hundred people with an intellectual disability living at Baillie Henderson Hospital and found that:

"they receive wholly inappropriate care because the staff who look after them are trained in psychiatric services but have no specific training or skill in helping someone with an intellectual disability. Perhaps the most obvious result is the persisting use of psychotropic medication as a form of behavioural control, even though it has no therapeutic benefit for these residents and creates its own range of organic illnesses and chemical addictions. We have met people at Baillie Henderson Hospital with no mental illness, who have been there for most of their lives, and have access to no allied health therapies or educational opportunities."⁴¹

³⁸ Ibid.

³⁹ Ibid xvi.

⁴⁰ Health Rights Commissioner, *Report to the Minister for Health and the Parliament of Queensland, on Investigations by the Health Rights Commissioner into Baillie Henderson Hospital, Toowoomba* (1996).

⁴¹ Ibid 76.

People with intellectual disability in mental health services

Approximately a decade on from these reports on the institutional abuse of people with intellectual disability being tabled in the Queensland Parliament, a further two reports published in 2006 continued to find evidence of inappropriate models of care for people with intellectual disability in health facilities:

- *Promoting Balance in the Forensic Mental Health System: Review of the Queensland Mental Health Act 2000* – a Report by Brendan Butler AM SC (Butler Report); submitted to the Queensland Government 8 December 2006, the Queensland Government Response Tabled in Parliament, 11 October 2007; and
- *Challenging Behaviour and Disability: A Targeted Response* – a Report by William Carter QC, (Carter Report) tabled in Parliament 22 May 2007.

Both the Butler and Carter reports noted that people with intellectual disability but no mental illness continued to reside in mental health hospitals in Queensland. This included those subject to a forensic order made by the Mental Health Court and those who, like the residents of Baillie Henderson Hospital, had neither a mental illness nor were subject to either a forensic order or an involuntary treatment order.

“It is necessary for the sake of completeness to draw attention to the fact that at Baillie Henderson hospital there are accommodated about 30/35 persons who have intellectual disability but who are not mentally ill. Some of these may have challenging behaviours. Many of this group are now quite elderly and have lived at Baillie Henderson for many years. Family members have supported this and it seems still do. A serious question arises as to whether they should continue to be supported as part of a mental health service.”⁴²

In response to the Butler and Carter Reports, the ten-bed Forensic Disability Service was opened on 1 July 2011 at the Wacol precinct for the purposes of providing a more appropriate forensic response for people with intellectual disability or cognitive impairment but no mental illness who are deemed to require detention in a secure facility.

The *Forensic Disability Act 2011* provides the statutory framework for the new facility. This facility is only for those people with intellectual disability or cognitive impairment subject to a forensic order (Mental Health Court - Disability) made by the Mental Health Court.

Lessons from deinstitutionalisation

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.⁴³ Similar findings have been

⁴² Carter, above n 12, 135.

⁴³ J Mansell and K Ericsson (eds), *Deinstitutionalization and Community Living: Intellectual disability services in Britain, Scandinavian and the USA* (London: Chapman & Hall, 1996).

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.⁴⁴

Many commentators caution against measuring the success of deinstitutionalisation by the numbers of people who leave institutions.⁴⁵ Community living is not just about a geographical location.⁴⁶ Without appropriate support, negative outcomes for people with intellectual disability moving into community can include homelessness, or what is known as ‘re-institutionalisation’ where they may end up in prison, nursing homes or psychiatric hospitals.⁴⁷

The same long-term study of people relocated from Challinor Centre that was discussed in a previous section also found that some people had not 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.⁴⁸

Good outcomes for people who are moved from institutions into the community are premised on community-based, person-centred planning and appropriate support. For example, in a long-term study of people with intellectual disability relocated from the Challinor Centre, those who demonstrated increases in adaptive behaviours were in environments where staff were actively involved in teaching, facilitating the acquisition of skills, providing opportunities for participation, behaving proactively, and fostering learning and individual development.⁴⁹

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 dual diagnosis (intellectual disability and mental illness), people with high and complex needs, or those labelled with 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.⁵⁰ Of those left behind after the wave of deinstitutionalisation, many are ageing.

The history of the relocation of people with intellectual disability from institutions in Queensland, including Baillie Henderson Hospital and the Challinor Centre, is testament to this. While the numbers of people began to decline from the 1980s onwards, those left were “the older, more physically handicapped or emotionally disturbed”.⁵¹ By 1995 for example there were 160 people still residing in Challinor Centre, 74% of whom had severe intellectual disability, challenging behaviours, specific health needs and a history of long-term institutionalisation.⁵²

Studies of deinstitutionalisation in Australia indicate that careful consideration should be given to the type of accommodation people are relocated to. The outcomes for adults with

⁴⁴ Young, Ashman and Grevell, above n 11, 52.

⁴⁵ Chenoweth, above n 34, 90.

⁴⁶ 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) 51-67.

⁴⁷ Chenoweth, above n 34, 86.

⁴⁸ Young, above n 5, 176.

⁴⁹ Ibid, 167-168.

⁵⁰ Chenoweth, above n 34, 88.

⁵¹ Young, above n 5, 62.

⁵² Ibid.

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”.⁵³

Evidence indicates that there needs to 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,⁵⁴ in which appropriate time and resources are devoted to making the relocation successful for the person with intellectual disability.

Summary

This section does not provide a comprehensive history of either institutionalisation or movements towards deinstitutionalisation in Queensland. In summary, however, it shows that the history of institutionalisation of people with intellectual disability in Queensland is similar to the history of institutionalisation of people with intellectual disability in many western and developing countries including the United States and United Kingdom.

While originally located with people with mental illness, early ‘reforms’ in the 1960s saw the separation of many people with intellectual disability from people with mental illness and the development of training centres and other facilities specifically for people with intellectual disability. The Challinor Centre at Ipswich was one such facility.

Queensland, like all jurisdictions in Australia, saw significant closures of large institutions and the relocation of people with disability to community living in the 1980s and 1990s, with an increase in community-based accommodation provided by government and non-government services. This movement was also given impetus by the uncovering of cultures of abuse and neglect of people with disability in some institutional facilities.

While in many cases outcomes for people were good, this was dependent upon access to appropriate support and appropriate accommodation.

At some point however these ‘reforms’ were stalled for a significant number of people with intellectual disability or cognitive impairment, many of whom remain living in long-stay health care facilities in Queensland. This is discussed further in the next four parts of the Report.

⁵³ 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.

⁵⁴ Maddison, above n 5.

Part 2: People in long-stay health care facilities in Queensland

Introduction

This part provides an account of the number of people with intellectual disability or cognitive impairment residing in long-stay health care facilities in Queensland including the numbers of people in each health facility, their median ages and length of stay in the facility.

People with disabilities remaining in health facilities

Despite the many reforms that took place in the 1990s in Queensland, there was not a wholesale change in the way that Queenslanders with intellectual disability were supported, with some people 'left behind' in institutions and new instances of institutionalisation arising.

First, not all institutions closed. For example, the Baillie Henderson Hospital did not close and there continues to be a number of people with intellectual disability or cognitive impairment who were not relocated as part of the original deinstitutionalisation movement and continue to reside there.

Second, new 'institutions' were built. For example, the Jacana Acquired Brain Injury Service at Bracken Ridge was built in 1985. Staff who were present at the time remember that a group of people who were 'deinstitutionalised' from Wolston Park were brought on a bus to the Jacana Acquired Brain Injury Service.

Third, new admissions continued and people with intellectual disability continue to be detained in authorised mental health services, including the Park Centre for Mental Health at Wacol and many other mental health services around Queensland.

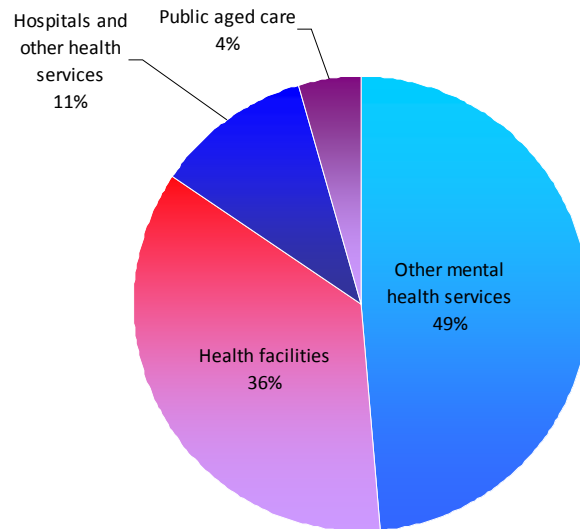
Department of Health data

There remain **271 people with intellectual disability or cognitive impairment residing in health facilities**, inclusive of mental health services, in Queensland.

Of these, **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** have been residing in **mental health services** in Queensland for both short and long periods of time.

Figure 1 People with intellectual disability or cognitive impairment in public health facilities



Source: Department of Health (July 2013)

Where are people with intellectual disability or cognitive impairment residing?

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%)**.
- 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%)**.

People in residential health care facilities (Table 1)

As of July 2013, there was a total of 131 people with intellectual disability or cognitive impairment residing in residential health care facilities. This includes Baillie Henderson Hospital, the Halwyn Centre and the Park Centre for Mental Health.

This group of facilities has the longest staying patients and includes those who were placed in these institutions as babies or small children and who have never been moved into the community.

The median length of stay varies according to the facility, with Baillie Henderson Hospital having the longest median length of stay at 40-45 years, with the longest staying resident having resided there for up to 65 years. Baillie Henderson Hospital is followed by Halwyn Centre (with a median length of stay of 25-30 years) then Jacana-Bracken Ridge (with a median length of stay 15-20 years), Jacana-Brighton (with a median length of stay 10-15 years), the Park Centre for Mental Health (with a median length of stay 10-15 years) and Casuarina Rehabilitation Centre (with a median length of stay 5-10 years).

The median age of residents also varies according to the facility with Baillie Henderson Hospital having the oldest group of residents, with a median resident age of 57, the oldest resident being 64 years.

Of the people with intellectual disability or cognitive impairment in residential health care facilities, approximately 61% are male and 39% are female.

Table 1: Long-stay patients (under 65 years) with intellectual disability or cognitive impairment residing in residential 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
Total	26	8	44	33	12	8

Source: Department of Health (July 2013)

People in aged care facilities (Table 2)

The Department of Health (Queensland Government) operates a small number of aged care facilities in which some long-stay patients with intellectual disability or cognitive impairment are residing.

There are a total of 12 people under the age of 65 years with intellectual disability or cognitive impairment living in public aged care facilities operated by the Department of Health. The median age of those people in aged care facilities is 56 years old, with the youngest aged at 46 years.

The median length of stay is under 5 years, although the longest staying resident has resided there for 15-20 years.

Table 2: Long-stay patients (under 65 years) with intellectual disability or cognitive impairment residing in aged care facilities operated by the Queensland Government, Department of Health

Median Age	56 years
Youngest	46 years
Eldest	63 years
Females	6 patients
Males	6 patients
Shortest Length of Stay	<5 years
Longest Length of Stay	15-20 years
Median Length of Stay	<5 years
Aboriginal and Torres Strait Islander	0 patients
Total	12 patients

Source: Department of Health (July 2013)

People in other public health facilities (Table 3)

There are a total of 30 people with intellectual disability or cognitive impairment residing for extended periods of time in hospital settings in Queensland. The Department of Health only provided aggregated data so it is only possible to report that, as a group, the patients have resided there for less than 5 years.

Table 3: Long-stay patients (under 65 years) with intellectual disability or cognitive impairment residing in public health facilities (hospitals)

Median Age	51 years
Youngest	18 years
Eldest	63 years
Females	11 patients
Males	19 patients
Shortest length of stay	<5 years
Longest length of stay	<5 years
Median length of stay	<5 years
Aboriginal and Torres Strait Islander	<5 patients
Total	30 patients

Source: Department of Health (July 2013)

People in mental health services (Table 4)

The Department of Health provided a specific set of data detailing the numbers and demographic profile of people with intellectual disability or cognitive impairment residing in mental health services in Queensland. This data had been collated by the Department of Health in May 2013, and is separate to the aggregated data collated by the Department in July 2013.

This group includes 132 people, inclusive of the long-stay mental health facilities such as Baillie Henderson Hospital and the Park Centre for Mental Health.⁵⁵ Of this group, 30 have been diagnosed with a mental illness and 7 with dementia; therefore there are approximately 95 people with intellectual disability or cognitive impairment and no diagnosed mental illness or dementia residing in mental health services in Queensland.

Given this group of people includes those people who have resided for very long periods of time in Baillie Henderson Hospital as well as those who have been there for very short periods of time, the median and average length of stays should be interpreted carefully. The longest length of stay was 62 years and the shortest length of stay one day, with the average length of stay 15.3 years.

There are 88 patients with intellectual disability or cognitive impairment who have resided in a mental health facility in Queensland for more than one year, and 59 who have resided in a mental health facility in Queensland for more than 10 years.

The eldest patient residing in a mental health service was 78 years and the youngest patient 16 years.

Table 4: People with intellectual disability or cognitive impairment residing in mental health services

Also diagnosed with Mental Illness	30 patients
Diagnosis of Dementia	7 patients
Subject to a forensic order	22 patients
Subject to an Involuntary treatment order	10 patients
Median Age	50 years
Youngest	16 years
Eldest	78 years
Females	53 patients
Males	79 patients
Shortest length of stay	1 day
Longest length of stay	62 years
Median length of stay	6.5 years
Average length of stay	15.3 years
Aboriginal and Torres Strait Islander	<20 patients
Total	132 patients

Source: Department of Health (May 2013)

⁵⁵ This number would be 98 people if Baillie Henderson Hospital and the Park Centre for Mental Health were excluded.

Cost of providing care to people with disability

The joint submission by the Department of Health and the Department of Communities, Child Safety and Disability Services indicated that the cost of providing services for people under 65 years of age in health facilities in Queensland in the 2012-13 financial year was \$76.28 million.⁵⁶

Indigenous people with disability in health care facilities

The data provided by the Department of Health indicates that there were fewer than five Aboriginal and Torres Strait Islander patients state-wide who have been residing for long periods of time in hospital settings (Table 3).

However stakeholders and key informants that work with Indigenous Queenslanders have indicated to the Public Advocate that this is unlikely to be an accurate figure.

Stakeholders report problems with the completeness of data sets, which impacts the ability to capture and report on Indigenous status. The data that does exist, they argue, fails to capture information in a way that might allow for the identification of indicators that could be used to assess the impact of prolonged periods of hospitalisation on Indigenous people and their families, particularly in relation to issues associated with being isolated from their cultural communities.

There is also a paucity of data to assess the adequacy of systemic responses that seek to minimise inappropriate hospitalisation or to effect meaningful reintegration to the community. For example, there are challenges associated with maintaining and/or redeveloping cultural connectedness for a person to support the success of their return to their community.

⁵⁶ 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. This submission noted that the estimate should be used with caution as it is based on a number of assumptions and excludes a number of variables, for example the allied health staff in our community health units who provide therapeutic and maintenance care and organise prescriptions for aids and equipment.

Part 3: Institutional care – are support needs being met in long-stay health care facilities?

Introduction

This part provides an overview of why supporting people with disability in institutional environments is not consistent with contemporary standards of care and support for people with disability.

Challenges to institutional care for people with disability

Institutional care of people with disability is premised on both a medical model of disability, which characterised disability as an illness, and a paternalistic approach to people with intellectual disability or cognitive impairment, that is, a perception that people with disability should be segregated from the general community to protect themselves and others.

The latter part of the twentieth century saw significant social changes, including a shift in the way that people with disability were perceived and growing recognition and advocacy for the equal rights of people with disability as citizens.

This movement was led by people with disability themselves, as well as by family members of people with disability and professionals.⁵⁷ There was a corresponding emphasis on the integration of people with disability into community and challenges to institutional models of care. This movement enabled recognition of the detrimental effects of segregating people with disability in institutions for people with disability, their family members and the community more generally.

Normalisation and Social Role Valorisation

The challenges to institutional care of people with disability and an increasing emphasis on community-based living were underpinned by the principles of *normalisation*⁵⁸ and *social role valorisation*, which in turn had a profound effect on disability policy, programs and services.⁵⁹

⁵⁷ M R Feigan, *The Victorian Office of the Public Advocate: A First History 1986-2007* (PHD thesis, School of Social Sciences, Latrobe University, 2001).

⁵⁸ Normalisation emerged as a concept in Scandinavian countries in the 1960s and was first conceived by Bank-Mikkelsen, and later developed by Nirje; N E Bank-Mikkelsen, 'A Metropolitan Area in Denmark: Copenhagen in Implications' in R Kugel and W Wolfensberger (eds), *Changing Patterns in Residential Services for the Mentally Retarded* (Presidential Committee on Mental Retardation, Washington D.C, 1969) 227–254; B Nirje, 'The Normalisation Principle and its Human Management Implications' in R Kugel and W Wolfensberger (eds), *Changing Patterns in Residential Services for the Mentally Retarded* (Presidential Committee on Mental Retardation, Washington D.C, 1969).

⁵⁹ Chenoweth, above n 34, 82.

Normalisation emerged as a concept in the 1960s⁶⁰ and was associated with assisting people with disability to lead as close to ‘normal’ lives as possible – accessing community living, education and employment for example.

Social role valorisation⁶¹ extended the concept of normalisation by advocating that the highest goal of normalisation should be the creation, support and defence of valued social roles for those who have been or are at risk of being devalued, including those with disability.⁶²

Community living for people with intellectual disability or cognitive impairment was consistent with the principles of both normalisation and social role valorisation, whereas it was recognised that institutional living was not. For example, for many people the idea of a home is a house located in a neighbourhood shared with family or friends.

It was submitted to the Public Advocate that the living conditions in most health facilities do not correspond with what many would call a ‘home’. People sleep in hospital beds, located in rooms shared with three or four other people and with scarce personal effects. Further to this, many health facilities remain situated on the outskirts of towns, or at least separated from neighbourhoods by parks, large grounds or high fences. In these living conditions, people with disability do not experience life as part of the community. In fact, their living conditions mark them as different. It was submitted to the Public Advocate that:

“if the current residents of health facilities lived in a house, in a neighbourhood, possibly with one or two other people, they would be part of the community, have opportunities to participate in local community life and develop friendships and acquaintances with their neighbours, local shopkeepers and others. Not only would this create a greater sense of inclusion and a higher likelihood that their social needs would be met, leading to overall improved well-being, but it would also mean that people with disability would be seen as ‘normal’ and valued parts of our communities.”⁶³

New models of support

Contemporary models of support and working with people with intellectual disability or cognitive impairment have continued to evolve over the years and are contributing to a greater value being accorded to the contribution that people with disability make to community.

Internationally and nationally there has been a reorientation of, or at least an aim to reorientate, disability services towards person-centred planning, a model that evolved during the 1980s.

Traditionally, service provision for people with disability was characterised by diagnosis and prescription or the identification of needs of a person by someone other than the person with disability and subsequent delivery of services within the available menu of support systems.

⁶⁰ Bank-Mikkelsen, above n 58.

⁶¹ Social role valorisation was developed by Wolfensberger. W Wolfensberger, ‘Social Role Valorisation: A Proposed New Term for the Principle of Normalization’ (2011) 49(6) *Intellectual Developmental Disability* 435.

⁶² Ibid.

⁶³ SEQUEL Association Inc, Submission No 3 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 15 July 2013.

Person-centred planning, however, focuses on facilitating the involvement of the individual to plan their own future.⁶⁴ Also called ‘self-directed planning’, it involves a focus on the needs, goals and aspirations of the person. It aligns with how people usually make decisions in their lives about where they want to live, how they want to live, where they would like to work and what extra skills they might need to learn to achieve their goals.

A pre-requisite to person-centred or self-directed planning is individualised funding. That is, the person must have funding allocated to them personally, not to the facility or service from which they are accessing support.

The Productivity Commission’s model for a National Disability Insurance Scheme (NDIS) was based on a person-centred approach that includes individualised funding. Many Australian states and territories are now also introducing self-directed approaches to the planning, funding and provision of disability services.

The United Nations Convention on the Rights of Persons with Disabilities

The *United Nations Convention on the Rights of Persons with Disabilities* (the Convention),⁶⁵ has heralded a more recent paradigm shift – 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 disabilities 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.⁶⁶

⁶⁴ K Callicott, ‘Culturally Sensitive Collaboration within Person-Centred Planning’ (2003) 18(1) *Focus on Autism and Other Developmental Disabilities* 60, 61.

⁶⁵ *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*’).

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 a 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 communities.⁶⁷

The model of care in Queensland's institutions

There is now an understanding that people with intellectual disability or cognitive impairment 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’ remained static, and that decision-making abilities could be developed, retained or, in some circumstances, exercised with assistance.”⁶⁸ Community living, with personalised and appropriate supports, is central to this approach.

Unfortunately, and in many cases despite the best of intentions, the models of care provided in the health facilities in Queensland in which people with intellectual disability or cognitive impairment reside do not meet these modern standards. In many respects, Queensland provides support to people with intellectual disability or cognitive impairment living in long-stay health care facilities in a manner that is not only archaic and outdated, but is in contravention of human rights instruments that the state of Queensland has a responsibility to uphold.

Many of the professional staff who are supporting this group of people and who tabled submissions and/or spoke with the Public Advocate are acutely aware that the type of support needed by people with intellectual disability or cognitive impairment cannot be provided in health care environments by medical staff.

⁶⁶ Ibid.

⁶⁷ P French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) *Human Rights Law Review* 8.

⁶⁸ R Creyke, *Who Can Decide? Legal Decision-Making for Others* (Department of Human Services and Health, Aged and Community Care Division, Commonwealth, 1995) 38.

The limitations of long-stay health facilities in meeting the support needs of individuals

Environment

The health facilities in which people with disability live are not home-like, even though many of these individuals have ‘lived’ there for 20, 30 and up to 65 years. Most people within this group sleep in hospital beds, in either a small hospital room or in a ward with other people. Most of the facilities look like any other hospital, except in many cases they are more ‘run down’ and furnished with hospital furniture. Lighting is like any other institutional-type lighting. It was submitted to the Public Advocate that the living arrangements at a particular 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.”⁶⁹

Privacy

These facilities are also often noisy and lack privacy, including a lack of privacy for family visits, with many residents vying for the attention of the few staff on shift. People may also be restricted from seeking privacy or ‘down-time’ in their own bedrooms at certain times of the day, and instead are expected to be engaged in group activities and/or to spend their time in common areas, even when this may not be their preferred arrangement.

Model of care

By their nature, facilities that are staffed predominately by nursing staff, allied health care professionals and support staff, also see a medical model of care predominating. This model of care and the often low ratio of staff to clients mean that most of the day is taken up with meals and personal care, with little opportunities for residents to be provided with individualised support, learn activities of daily living or even have the opportunity to feed themselves at dinnertime.

“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.”⁷⁰

⁶⁹ 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.

⁷⁰ 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.

Individual choice and decision-making

The size and nature of the facilities often mean that they operate according to strict routines, such as 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). Unavoidably, an institutional model of care means staff making all kinds of choices for residents, rather than residents making choices themselves. For residents with communication difficulties there may be no opportunities to make decisions although everybody, even people who do not have capacity to verbalise, usually have a way to make their preferences known.

A family member of a person residing in a health facility submitted to the Public Advocate (this report does not use the client's real name or the name of the facility):

"Staff cannot be person-centred when there are so many people to support...Michael* does not get a choice in what he eats, wears or does. He sleeps in a room with another man, and when asked, the centre said that he was not able to have his own room, despite Michael requesting this on his communication device. ..When asked if he had any friends living [at the centre], Michael replied with NO."⁷¹

Social opportunities

People in institutions are often grouped together regardless of their ages, likes and dislikes, or level of ability. This means that people with disability often live with people much older or younger than them, or even people they do not like or would not naturally choose to live with. On the other hand, some residents have formed meaningful friendships and have indicated that if they ever were able to leave the institution, they would like to live together.

Opportunities to learn and develop

In these environments, people's functional capacity often decreases. With things being done 'to them' and 'for them', they do not have the opportunity to learn how to care for themselves. It is very unusual, for example, for residents to be able to make themselves a cup of tea or even a meal as simple as toast. Rather they have to wait for the designated meal times when food is brought to them and in many cases, to save time, fed to them rather than have the opportunity to learn to feed themselves. Educational and vocational opportunities are often absent.

Confinement in the facility

In many cases residents cannot voluntarily access outside areas such as the grounds of the facility. Many residents are confined on a daily basis to the facility in which they reside and in the absence of activities there is often little to do except watch television, sit or walk around the facility.

* The resident's real name has not been used.

⁷¹ Confidential, Submission No 1 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 17 June 2013.

The Public Advocate spoke to one man at a health facility where she visited. When asked what he does during the day, he said “I smoke and I watch TV”. This man had good communication skills, was mobile and, despite having waited 10 years for funding to move out of the facility, had a lively sense of humour.

Community participation

There is little access to the community for most residents, and no access at all for many. Nor is there access to educational or vocational opportunities for people.

Health

While many people’s basic needs such as shelter and food are met, it was submitted to the Public Advocate that people’s general health suffered overall in institutional environments. Many family members said that they had seen a marked deterioration in their family member’s health and general well being. Some staff indicated that many people’s medical needs would in fact be better met in the community, with access to experienced general practitioners and community-based allied health care.

Cumulative impact

A family member of a person who has resided in a health facility for many years made the following statement:

“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 systemic deterioration of eating, digestion, elimination), and her muscles have atrophied and stiffened. Sophie has also been denied the right to a good education and work opportunities, and the right to develop healthy relationships. Instead she has lived a wasted life with a lack of purpose, loneliness and isolation, in a segregated environment filled with a medical routine.”⁷²

Parents of a man with intellectual disability who has been living in a health facility for 25 years submitted to the Public Advocate that they had given up hope of their son ever moving from the facility in which he was residing and receiving better care.

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

⁷² Confidential, Submission No 7 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

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 was 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.

The Public Advocate's office explained to the parents that neither they nor their son would be identified in the report. The parents were greatly concerned not to be identified because they believed in some way it would affect their son's support.

The family are still waiting on funding from Disability Services for their son to move out of the facility, but they are both now getting much older and, while still concerned for his future, have almost 'given up'.⁷³

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

⁷³ Confidential, Submission No 2 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 10 July 2013.

Part 4: People with intellectual disability in long-stay health facilities

Introduction

This part provides more information about people with intellectual disability in long-stay health care facilities and issues that should be taken into consideration to support their successful transition to community-based living where appropriate and desired.

Within this group there are two general subgroups that the Public Advocate has identified – those who have resided in health facilities most of their lives and ‘missed out’ on moving to the community in the first wave of deinstitutionalisation; and those who are residing in mental health services because of the lack of more appropriate services and/or adequate levels of support to meet their needs.

It would also appear that a third group may be emerging, that being people in emergency or crisis situations whose community arrangements have broken down. These individuals are often moved to such facilities, ostensibly on a short-term basis, but unfortunately remain there far longer than intended due to a lack of appropriate funding, support and/or housing options.

Those who ‘missed out’ on deinstitutionalisation in Queensland

There are a group of people in Queensland with intellectual disability who unfortunately ‘missed out’ on the first wave of deinstitutionalisation and now remain ‘stuck’ in institutional settings. As they grow steadily older, they also become increasingly frail. This group of people are primarily residing in residential health care facilities, including places that were originally built to ‘house’ people with intellectual disability such as Baillie Henderson Hospital (where people with intellectual disability have resided since it opened in 1890) and the Halwyn Centre at Red Hill.

Halwyn Centre, Red Hill

The Halwyn Centre at Red Hill accommodates 44 residents with intellectual disability or cognitive impairment. The median length of residence is 25-30 years, with the shortest stay 5-10 years and the longest 30-35 years.

Few people at Halwyn have individualised packages of funding from Disability Services. The SEQUEL Association Inc receives 22 hours of block funding from Disability Services to provide community access for some residents. Like many other places, some people at Halwyn also save money from their pension entitlements (after having paid a contribution to their accommodation at Halwyn) to pay for community access. SEQUEL also takes clients on occasional holidays.

Halwyn Centre, Red Hill (continued)

The staff at SEQUEL spoke about the enjoyment that residents get from community access and holidays and how even those residents who have spent decades in Halwyn and whose skills have deteriorated, 'come alive' when given the opportunity to experience life in the community.

In fact, SEQUEL Association Inc was started by a group of families and professionals connected to the residents at the Halwyn Centre. This parent group was concerned that there was a growing gap between the complex needs of their adult sons and daughters and the support they were receiving after leaving school.

While some family members are happy to have their son or daughter remain at Halwyn, where they know they will be safe and cared for, a number of family members and residents would like to move into community-based living. Some parents have been trying for 10-15 years to get their son or daughter assessed and prioritised for funding from Disability Services. As parents age, and after years of trying with no results, it has been reported to the Public Advocate that they get tired of the effort, become depressed and give up.

SEQUEL has supported three people to go through the assessment process with Disability Services, but with no results.

Baillie Henderson Hospital

Baillie Henderson Hospital is situated on the outskirts of Toowoomba. It was originally built in 1890 as the Toowoomba Mental Health Hospital and from then onwards has accommodated people with intellectual disability. Many entered the hospital when they were young children and never left. Many people with intellectual disability were also transferred there from other services such as Wolston Park Hospital, Challinor Centre, Ipswich Special Hospital and the Toowoomba Epileptic Home.

Baillie Henderson Hospital is now a 180 bed tertiary mental health facility, funded by the Department of Health to deliver mental health services and programs.

Despite a 'no admissions policy' since the early 1990s for people with a sole diagnosis of intellectual disability, there are 26 residents with intellectual disability or acquired brain injury who remain there, ranging in age from 36 to 64 years with varying length of stays from 10 up to 65 years.

Baillie Henderson Hospital (continued)

It has been acknowledged that many of these 26 clients had been “lost to their families, with family members being advised by the authorities at the time to put their loved one into an institution and forget about them. Over the past two decades much effort has been put into finding the families of these residents, with sometimes difficult family reconnections being made.”⁷⁴

It was submitted to the Public Advocate that “this group of people have ‘missed out’ on the opportunities other people with intellectual disability had to access more appropriate models of care and move into community-based living.”⁷⁵

Despite the limitations, staff provide the best possible care in the circumstances and work to seek alternative community accommodation models and explore options to provide community access for residents. For example, all residents have their finances (their pension entitlements) managed by the Public Trustee. Around a decade ago, in response to the lack of community access by residents, staff took the initiative and made an application to the Public Trustee for a number of clients to ‘purchase’ their own ‘support worker hours’ to enable them to access community-based activities. The first resident purchased their own support for community access in June 2002.

Now the local non-government organisation, Warrina Services, is provided with ‘block funding’ to provide some community access on a weekly basis. Staff say this community access has provided an opportunity for residents to enhance their lives by being involved in activities outside of the mental health hospital. Feedback from staff is that residents are enjoying their outings and family members are delighted with the provision of the service, which they view as having improved the quality of life for their loved ones. On some occasions, this service is provided to assist residents to visit family members.

It was submitted to the Public Advocate that “an assessment by Dr Michael Kendrick in 2010 supported the intent that it would be possible and would be beneficial from a care and quality of life perspective, to relocate some of these people to community accommodation but this would require whole of government commitment and dedicated resources to facilitate a systems response and at the same time guarantee a robust response at an individual level. If this were to happen it would go a long way to meeting our obligations from a human rights perspective and the United Nations Conventions.”⁷⁶

⁷⁴ Rogers and Wigan, above n 2, 3.

⁷⁵ Ibid 6.

⁷⁶ Ibid.

Baillie Henderson Hospital: calls for reform ignored

Over time the group of residents at Baillie Henderson Hospital have been the subject of numerous recommendations of taskforces and other reports focused on the provision of more appropriate accommodation, support and services for the residents with intellectual disability living in this facility.

In 1989, the Ministerial Taskforce on Services for People with an Intellectual Handicap in Queensland tabled its report, *A Place for Everyone*, in the Legislative Assembly.⁷⁷ This report focused on a proposal for community services provisions and development for people with an 'intellectual handicap'. The report recognised that there were continuing concerns about people with intellectual disability (including children) who continued to reside in health facilities such as Baillie Henderson Hospital.

The report recommended the relocation of the residents in Baillie Henderson Hospital to community-based facilities:

"A number of comments were also made about government facilities other than I.H.S. facilities that provide residential services to people with an intellectual handicap. Concerns were expressed about people with an intellectual handicap still resident in psychiatric hospitals (Baillie Henderson Hospital in Toowoomba and Mossman Hall in Charters Towers) and about people in nursing care units at the Base Hospitals in Maryborough and Rockhampton. In general, the concerns expressed were not about the type of care received by people in these facilities but about the appropriateness of people with an intellectual handicap being cared for in these types of facilities. It was suggested that, while some people may have special care needs, the majority of these people did not need the level of medical care provided and could be well placed in smaller community-based facilities.

I believe these children could be housed in a more appropriate setting... with considerable benefit to their lives."⁷⁸

Throughout the years that followed numerous reports echoed similar concerns and came to the same conclusions including:

- *Report to the Minister for Health and the Parliament of Queensland on investigations by the Health Rights Commissioner at Baillie Henderson Hospital, Toowoomba*, Tabled 26 November 1996. In this report, **the Commission recommended that:**

"the Government should find means by which the Department of Family, Youth and Community Care can assume responsibility as soon as possible for the care of people with an intellectual disability now resident in Baillie Henderson Hospital; and in the meantime, the current use of medication regimes, the lack of allied health services, and the absence of appropriately skilled staff should be rapidly addressed as a transitional part of the institutional reform process."⁷⁹

⁷⁷ Ministerial Taskforce on Services for People with an Intellectual Handicap, above n 8.

⁷⁸ Ibid.

⁷⁹ Health Rights Commissioner, above n 40, 76.

- *Challenging Behaviour and Disability: A Targeted Response* - a Report by William Carter QC, tabled in Parliament 22 May 2007. Mr Carter QC recommended that:

“Disability Services Queensland and Queensland Health engage collaboratively in determining the preferable option(s) for accommodating those persons with intellectual disability only who are and have been for many years accommodated and cared for at Baillie Henderson Hospital.”⁸⁰

The residents of Baillie Henderson Hospital

While some people were relocated from Baillie Henderson Hospital in prior years, many remain there. Some of the people who reside there are now older and more frail. The residents of Baillie Henderson Hospital are often spoken about as a single group who, because of their age, complex medical needs and disabilities, are not suited to community-based living.

It has been emphasised to the Public Advocate however that they are all individuals who have different needs, goals and issues that must be taken into account when considering both an improvement in their current models of support and whether a move to community-based living would be appropriate. Of the 26 patients residing at Baillie Henderson Hospital the staff categorised them into three groups:

Group One: This group of people are described as quite high functioning, independent and mobile compared to some of the other ‘patients’ in the facility. The Public Advocate spoke to a number of residents, visited their rooms and talked to them about what they did to occupy themselves in the hospital during the day. Some people, despite their confined and restrictive environments, had found creative ways to occupy themselves in the facility, for example, making and selling craft items they had made and running a small ‘canteen’ for staff and residents. Many really looked forward to their day for ‘community access’ when they had the chance to leave the facility for a little while. Three of this group live in a dual diagnosis unit for people with mental illness, even though they do not have a currently diagnosed mental illness.

Group Two: This group of people have been described as having severe intellectual disability and varying levels of physical disability. Some do not communicate verbally. The length of stay for this group is considerable, with some having come to the institution as small children. They need regular review by allied health staff (such as dietitians, physiotherapists, speech pathologists, etc) as well as ongoing monitoring, review and treatment by medical and nursing staff. It was submitted to the Public Advocate, however, that this care could be provided in the community as ‘is the process for many people with similar disabilities living in the community away from an institutional type model.’ Despite their high medical and support needs, this group of people are not eligible under the Queensland Government’s Medical Aids Subsidy Scheme, and must purchase their own specialised personal medical equipment out of their own pension entitlements. That is, after they have paid 66.67% of their disability pension towards the ‘fee’ charged to reside in the facility.

Group Three: There is a small group of people with acquired brain injury and high physical care needs. Two of these people were admitted 30 and 31 years ago as young people with acquired brain injury for rehabilitation following discharge from hospital, but have never left. The individuals in this group of people are ‘registered with Disability Services’ but have not received funding to move out. It was submitted to the Public Advocate that, as time moves on,

⁸⁰ Carter, above n 12, 23.

the only option now may be to wait until their age and physical condition deteriorates to the extent which requires them to move into a nursing home.

Disability: a medical problem?

The implications of a health model of care for people with intellectual disability

The long-stay health care facilities where people with intellectual disability have been residing are administered and operated by the Department of Health.

The ongoing residence of people with intellectual disabilities in health facilities, operated and administered by the Department of Health, has a number of systemic implications for the people who reside there.

Isolation from community in congregate care environments

Living in large hospital and health facilities inevitably means segregation from the general community.

The residents in Baillie Henderson Hospital are housed in ward-like rooms, inside large brick buildings, segregated from surrounding neighbourhoods by very large hospital grounds.

The residents at Halwyn Centre are similarly located in hospital ward type rooms, in a large multi-storey building, separated from the general community by a park, a special school and a busy arterial road.

Segregation of people with intellectual disability from the community not only encourages stigmatisation and discrimination against people with disability but it also has a profound effect on the self worth of people with disability and the extent to which they feel included in the community.

Needs are not and cannot be met in an individualised manner

Residing in health facilities, people with disability do not have individualised funding packages. Rather the health facility is funded to provide services in relation to a certain number of 'beds'.

The extent to which people have the opportunity to engage in personalised planning about their future and goals, and obtain services and supports to develop adaptive functioning skills and reach their full potential, like other people with disability who live in community-based accommodation do, is often extremely limited.

Even where facilities undertake some measure of personalised planning with people with disability residing there, without access to individualised funding, there is no possibility of implementing that plan in an optimal way. Funding is provided to run the facility and meet the residents' direct care needs, not for their individual development.

This model of care can only result in a loss of choice, self determination and autonomy.

Staffing by health staff

Health facilities are inevitably staffed by health staff, including nursing staff. These staff are dedicated health professionals who the Public Advocate has heard from many commentators provide a good standard of care to the people with disability living in these facilities. The health professionals that the Public Advocate met with were extremely dedicated, caring and hard working people who are committed to doing their best for the residents in their care.

It was submitted to the Public Advocate, however, that the type of care provided to many of the people in health facilities is limited not only by the professional backgrounds of the staff who care for them but also the extremely low staff to patient ratio in some facilities. Particular industrial awards may also limit the type of care and support that can be provided.

Staff are often limited in the amount of time that is able to be spent with people with disability teaching skills such as cooking, self care and house care. With many people with disability to care for, some with much higher needs than others, most of their time is taken up with direct personal care and feeding.

Access to health care

It is acknowledged that some people with disability residing in long-stay health care facilities such as Baillie Henderson Hospital and Halwyn Centre do have complex health and medical needs, additional to their intellectual disability, that require review and treatment by medical and allied health professionals. However facilities such as Baillie Henderson Hospital and Halwyn Centre are not hospital facilities in the sense of acute or sub-acute facilities. Rather they are staffed by health professionals, usually nurses, as well as other non-professional support staff. As was submitted to the Public Advocate in relation to a group of people who reside in Baillie Henderson Hospital with high medical care needs, this type of medical care can and does get provided in community settings.

It was also submitted to the Public Advocate by health professionals working at these facilities, including a medical practitioner, that paradoxically people's health needs are not always best met by residing in a health facility. Access to a wider range of health and allied health care professionals, including experienced general practitioners, is enhanced for people who live in the general community. Further, relatives of people who reside in these facilities have spoken about a general deterioration in the health of their family member with disability including problems with dental health and atrophy of muscles.

Issues for transition to community-based living

The Public Advocate asked about the issues that should be taken into account to support successful transition from institutional to community-based living, where appropriate and desired.

(i) Choice and a person-centred response

Overwhelmingly the submissions to the Public Advocate spoke about the importance of treating each person as an individual and offering choices to both them and their families. What may suit one person and their family would not suit everyone.

“The Public Advocate’s endeavours in this area are commendable. It is however a difficult thing to try and be all things to all people. We are all different, and with different needs. We cannot collectively be put in the same box. Some people are well suited to a set of circumstances. Other people are totally ill-suited to those same circumstances.”⁸¹

Some people have complex medical needs that may require ongoing monitoring, review and treatment and others do not.

Some residents have formed close bonds and friendships with other residents and have expressed the desire, if they had the opportunity to live in the community, to share a house with their friends. For some residents, their families have moved closer to the facility in which they are residing, while other family members live a long way away.

A crucial starting point is individualised funding for all the residents so that a personalised planning process can be carried out based on comprehensive and thorough individual assessments. Access to individualised funding was emphasised by many with Queensland Advocacy Incorporated submitting:

“With the opportunity to plan for a future life in the community, residents of institutions must be supported with individualised, portable funding. They must also be allowed the right to choose: whether they will self-direct and self-manage their own funds; who they will engage to deliver supports and services; and most importantly where, with whom they live.”⁸²

(ii) Appropriate destinations and models of support

In a submission to the Public Advocate in relation to people with intellectual disability living in Baillie Henderson Hospital it was said:

“In considering what needs to occur in the best interests of this group of people, an individual approach, based on their biopsychosocial needs is needed. There are some people in this group who may have an improved quality of life by being accommodated closer to family members in the community. It would be naïve to think that by simply housing all of these people in small group homes in the community would somehow improve their lives without a refocus of care and concerted effort to integrate them into the community.”⁸³

Many commentators reflecting on past deinstitutionalisation reforms have cautioned against measuring the success of deinstitutionalisation by the numbers of people who leave institutions.⁸⁴ Community living is not solely about a geographical location.⁸⁵

Most importantly, the sister of one resident of a long-stay health facility said, they need to “live in a place that they can call ‘home’ in the true sense of the word.”⁸⁶

⁸¹ Confidential, Submission No 9 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

⁸² Queensland Advocacy Incorporated, Submission No 17 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 16 August 2013.

⁸³ Rogers and Wigan, above n 2, 6.

⁸⁴ Chenoweth, above n 34, 90.

⁸⁵ Bachrach in Bruininks et al (eds), above n 46.

⁸⁶ Confidential, Submission No 7 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

Without appropriate support, negative outcomes for people with intellectual disability moving into the community can include homelessness, or what can be seen as ‘re-institutionalisation’, whereby they may end up in prison, nursing homes or psychiatric hospitals, or move between these facilities.⁸⁷

While there is strong evidence to suggest that smaller, dispersed community housing tends to provide more opportunities and improved outcomes for people,⁸⁸ 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 Development Disability Studies, states that best practice in service delivery would offer people a range of accommodation and support options to suit their preferences and needs, which may change over their lifetime.⁸⁹ Although it must be stated that many submissions to the Public Advocate cautioned against, or were absolutely opposed to, moving people from institutions to congregate-living facilities in the community.

(iii) A participatory and planned response

There needs to be a community-based approach to planning with a concomitant focus on the individual, including their interrelationships with people in the institution from where 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 the relocation of people must be a ‘bottom-up’ process,⁹⁰ where appropriate time and resources are devoted to making the relocation successful for the person with intellectual disability and their families.

National Disability Services said that it is important to involve and engage people with disability and their families and carers from the beginning to find solutions and understand the issues, including:

- providing people with opportunities to be involved, share information and build their capacity to engage thorough a participatory process;
- working with people to identify potential barriers and fears, provide adequate support and build skills and capacity to make meaningful choices about where they want to live and with whom;
- deliver information and communicate in a variety of accessible formats to meet individual needs;
- deliver clear timeframes and plans; and
- build workforce capacity within the long-stay health care facility to engage effectively in the transition process.⁹¹

Queensland Aged and Disability Advocacy Service Inc (QADA) talked about the importance of supporting people with disability to make their own decisions.

⁸⁷ Chenoweth, above n 34, 86.

⁸⁸ 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.

⁸⁹ Parmenter and Arnold, above n 88, 10-11.

⁹⁰ Maddison, above n 5.

⁹¹ National Disability Services, Submission No 10 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013, 3.

“Recently, an evaluation of the pilot project on supported decision-making in South Australia found that this was a viable option for decision-making; in addition the process of supported decision-making was positive for the participants involved. In order for this to occur training and education around this process is required for independent trusted individuals; alternatively resources are needed to fund independent supports such as advocacy services to assist people with intellectual disability or cognitive impairment with their day to day decision-making. Utilising assisted communication tools and methods such as electronic systems, pictures and photos, as well as taking the time to understand resident’s needs, including their life before entry into residential aged care to inform understanding of likes and dislikes will also assist with communication barriers.”⁹²

(iv) Consultation with and consideration of the views of family members

Consultation with and consideration of the views of family members is important.

Many people have parents and other family members who have been desperately advocating over years for their son, daughter, sister or brother to receive funding and assistance to move into more appropriate community-based accommodation. Others have family members who are aging and concerned about what might happen to their son or daughter if they did not live in a government-run health facility.

Submissions to the Public Advocate from some family members expressed significant concern about the prospect of their son or daughter moving from the facility in which they are living.

Some family members have also repeatedly had their expectations raised over the years only to be repeatedly disappointed.

It was submitted to the Public Advocate that careful consideration needs to be given to the feelings and concerns of family members, many of whom may have placed their son or daughter in the institution as babies or young children when there was much pressure to do so and no support available to care for them at home.

(v) High level support, coordination and resourcing

Although planning has to happen with the person and their families within the context of local community, commentators 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. It was agreed by many that protocols should be developed between health, housing and disability services at the highest levels of the respective departments to pave the way for easier and more coordinated transitions at local community levels.

⁹² Queensland Aged and Disability Advocacy Inc, Submission No 11 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 2 August 2013.

Many also spoke about the importance of committed resources to transition people from institutional environments. Many families have unfortunately been promised changes for their family members before, only to be disappointed when funding was suddenly not available or reallocated. Many people with disability in institutions have been assessed as eligible only to then wait years with no outcome.

(vi) More opportunities including more community access

Despite whether and when people transition to community-based living, many people spoke to the immediate need for improved access to community, and opportunities to learn daily living skills as well as educational and vocational opportunities. Some family members also asked that greater care be taken to maintain the health facilities in which their family members live.

“Such waste, when you already have the buildings, do them up the same as you would your own home, there is no end to what can be done when you have it already in place, it’s a sin to see such buildings go to waste, you don’t see other countries let good buildings go to waste. In the past there were nice gardens and surroundings to create an atmosphere, now it is all gone and very bare and looking neglected, all that has been done in the past like activities etc has been given the chop.”⁹³

Particular concern was also expressed about the lack of support to maintain and develop means of communication, including access to speech therapy. Family members in particular were distressed about circumstances where their family members who are residing in health facilities are not supported to communicate. Many had noticed their relative’s communication abilities diminish the longer they lived in the health facility.

People with intellectual disability but no mental illness residing in other mental health services

While the data provided to the Public Advocate from the Department of Health identified **132 people with intellectual disability or cognitive impairment residing in mental health facilities** in Queensland in May 2013, this total included both those who had resided there for up to 65 years and those who had resided there for one day, so it must be treated with caution.

However, it is known that:

- **88 patients** with intellectual disability or cognitive impairment have resided in a mental health facility in Queensland for **more than one year**; and
- **59 patients** have resided in a mental health facility in Queensland for **more than 10 years**.

Access to appropriate models of care

From the data provided by the Department of Health to the Public Advocate, it seems that of the 132 people residing in mental health services:

- **Approximately 95 people** have a sole diagnosis of either intellectual disability or cognitive impairment and no diagnosed mental illness or dementia.

⁹³ Confidential, Submission No 14 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 6 August 2013.

In the previous review of the *Mental Health Act 2000* conducted by Brendan Butler AM SC in 2006, it was recognised that despite the purpose, principles and schema of the *Mental Health Act 2000* only applying to people with mental illness, people with intellectual disability were also being captured by the provisions of the Act. This was primarily because of those provisions of the Act dealing with criminal charges and forensic orders.

In addition to identifying the inappropriateness of detaining people with intellectual disability and no mental illness in authorised mental health services, Butler AM SC stated that:

“It would appear that the reason people with an intellectual disability who commit serious offences are dealt with under the *Mental Health Act 2000* is that there are no alternative legislative or service arrangements for people with an intellectual disability who require secure care. The *Disability Services Act 2006* (and its predecessor) does not contain analogous provisions to the civil or forensic provisions in the *Mental Health Act 2000* for the involuntary care and treatment of people with a mental illness.”⁹⁴

In *Promoting Balance in the Forensic Mental Health System: Final Report Review of the Queensland Mental Health Act 2000* (the Butler Report), Butler AM SC recommended that “a review of the provisions of the *Mental Health Act 2000* affecting people with intellectual disability be conducted as part of any reform to provide secure care for people with intellectual or cognitive disability who exhibit severely challenging behaviour.”⁹⁵

In 2006, the Honourable William Carter QC also commenced a review in relation to “existing provisions for the care, support and accommodation of people with an intellectual/cognitive disability who represent a significant risk of harm to themselves or the community.”⁹⁶ The final report *Challenging Behaviour and Disability: A Targeted Response* (the Carter Report) also identified the inappropriateness of placing people with intellectual disability in authorised mental health services, as well as the fragmented response to the cohort of people with intellectual disability who exhibit challenging behaviours generally, regardless of whether they are subject to a forensic order.⁹⁷

In response to the issues raised by both the Butler and Carter reports, the ten-bed Forensic Disability Service opened at the Wacol precinct in 2011. *The Forensic Disability Act 2011*, which commenced on 1 July 2011, provides the statutory framework for the ten-bed Forensic Disability Service but does not enable a holistic system response to ensure coherent, consistent and integrated care and support options for those people with intellectual disability or cognitive impairment in mental health services.

A person may be subject to a forensic order if they are alleged to have committed a serious criminal offence and they have been found unfit for trial or unsound of mind by the Mental Health Court. A forensic order detains a person to a specific mental health service or the Forensic Disability Services.

From the available data it seems that there are **16 people** with an intellectual disability but no mental illness who are subject to a forensic order but are **not detained to the Forensic Disability Service** in Queensland.

⁹⁴ B Butler, *Promoting Balance in the Forensic Mental Health System: Final Report Review of the Queensland Mental Health Act 2000* (2006) 101.

⁹⁵ Ibid 102.

⁹⁶ Carter, above n 12, 4.

⁹⁷ Carter, above n 12, 87.

This means that these people cannot benefit from the model of care provided to those who are detained to the Forensic Disability Service, where it is mandatory to have a multidisciplinary model of care aimed at promoting the client's development, habilitation and rehabilitation; reducing the intensity, frequency and duration of the client's behaviour that places the client's health or safety or the safety of others at risk; and when appropriate, supporting the client's reintegration into the community.⁹⁸

Involuntary treatment of people with intellectual disability but no mental illness

The available data also indicates that there are approximately a further **75 people** with an intellectual disability and no mental illness residing in a mental health service, but **not subject to either a forensic order or involuntary treatment order**.

The Queensland Law Society submitted that people with intellectual disability or cognitive impairment seem to be placed in health facilities under a number of different mechanisms including:

- a referral by their statutory health attorney or attorney appointed pursuant to an enduring power of attorney;
- a decision by the Adult Guardian or another guardian appointed by order of QCAT; or
- a forensic order by the Mental Health Court.

The Queensland Law Society argued that the multitude of entities involved and varying legislation adds a degree of complexity and that there should be more access to justice for these persons as well as less red tape and overlap between entities.⁹⁹

⁹⁸ *Forensic Disability Act 2011* (Qld) s 15.

⁹⁹ Queensland Law Society, Submission No 15 to the Public Advocate, *People with Disability in Long-Stay Health Care Facilities*, 9 August 2013.

Part 5: People with acquired brain injury in long-stay health facilities

Introduction

This part provides information about people with acquired brain injury in long-stay health care facilities and the issues that need to be addressed to support successful transition from institutional to community-based living.

Acquired brain injury

Acquired brain injury (ABI) refers to the multiple disabilities arising from damage to the brain that occurs after birth. Damage to the brain may be caused by an accident or trauma, by a stroke, a brain infection, by alcohol or drugs, or diseases of the brain like Huntington's disease.¹⁰⁰ It differs from intellectual disability, which is characterised by significant limitation in intellectual functioning and adaptive behaviours such as conceptual skills, social skills and practical skills, that become apparent prior to 18 years of age.¹⁰¹

Almost one in 45 Australians is affected by an ABI-related disability. Queensland has the highest national rate of ABI compared to all other states and territories. In 2003, there were 82,600 people living with an ABI-related disability in Queensland.¹⁰²

The international literature recognises that ABI is a leading and increasing cause of disability world-wide.¹⁰³ It is also anticipated that the number of people with ABI in Queensland will grow as more people survive brain injuries sustained through accidents, stroke, assaults and a range of other causes each year. In 2004-05 alone, there were over 8,300 hospital admissions in Queensland related to acquired brain injury.¹⁰⁴

People with ABI can experience a range of disabilities that will affect them both physically and also in the way they think, feel and behave.

¹⁰⁰ Brain Injury Australia, Submission No 371 to the Australian Government Productivity Commission, *Disability Care and Support*, 16 August 2010, 1.

¹⁰¹ Adapted from the definition of the American Association on Intellectual and Developmental Disabilities; American Association on Intellectual and Developmental Disabilities, *Definition of Intellectual Disability*, American Association on Intellectual and Developmental Disabilities <<http://aaidd.org/intellectual-disability/definition>>.

¹⁰² Australian Institute of Health and Welfare, *Disability in Australia: Acquired Brain Injury* (Bulletin no.55 Cat no. AUS 96, Australian Government Canberra, 2007) in Quarterly Brain Injury Services Meeting (QBISM) Group, above n 3, 2.

¹⁰³ Brain Injury Australia, above n 100, 1.

¹⁰⁴ B Turner and D Doherty, *Princess Alexandra Hospital: Brain Injury Rehabilitation Services 2010 Service Model Development – Benchmarking/Service Enhancement Report* (Princess Alexandra Hospital, Brisbane, 2006) in QBISM Group, above n 3, 2.

“Physical disabilities can include headaches, fatigue, seizures, poor balance and coordination, paralysis, loss of the sense of taste or smell and vision or hearing disturbance. Many people with an ABI live with cognitive disability such as poor memory and concentration, a reduced ability to learn, to plan and to solve problems. In addition, almost two out of every three people with an ABI will exhibit shifts in their behaviour including increased irritability, poor impulse control, verbal and sometimes physical aggression. These behaviours are often due to damage to particular areas of the brain. However, they can also have been learned or adopted as a response to disability.”¹⁰⁵

However there is much evidence that early and sustained access to intensive rehabilitation after an ABI helps to reduce disability, restore function and improve participation.¹⁰⁶

Where are people with ABI located in Queensland?

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.

Acute hospital settings

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.

In a survey conducted by the Department of Health in March 2012, it was identified that there were **64 people with a disability in acute hospital beds** in Queensland. Of the 64 people with disability 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**.¹⁰⁷

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 enter aged care facilities.

¹⁰⁵ QBISM Group, above n 3, 19.

¹⁰⁶ Ibid.

¹⁰⁷ Department of Communities, Child Safety and Disability Services and Department of Health, above n 56, 11.

As the Young People in Nursing Homes National Alliance submitted, 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.

‘Residential’ long-stay health care services

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.¹⁰⁸

For example, there are currently **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 are also **12 people in Jacana Acquired Brain Injury Service Brighton** and **8 people in Casuarina Rehabilitation Centre who are long-stay residents of these facilities**.

Jacana Acquired Brain Injury Service

While Jacana Acquired Brain Injury Service was originally established as a residential service for young people with acquired brain injury in 1985, 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 now 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.

¹⁰⁸ 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.

Jacana Acquired Brain Injury Service (continued)

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, a few 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).

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 is the first time that the woman had been offered an opportunity to make a decision about her diet in 13 years.

Mental health services

People with acquired brain injury are also in Queensland mental health services, with **23 people identified with an ABI residing in mental health services**, the longest length of stay being **31 years**.

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 that are sorely needed in Queensland.

The cost of staying in hospital beds versus community-based living with support and therapy

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)¹⁰⁹ highlighting that 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.

¹⁰⁹ 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, Rehability, Edge Rehabilitation, Coastal Rehab, Integrate Rehab, Neuro Rehab Solutions, BE Lifestyle, The University of Queensland, Griffith University.

Table 5: 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).

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 calculated that it cost \$1,200 per day to care for a patient in a sub-acute hospital bed. The cost of supporting a person to live in the community can 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 one-hour sessions of private therapy).

An 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.¹¹⁰

¹¹⁰ QBISM Group, above n 3, 19.

The Young People in Nursing Homes National Alliance points out that this issue, combined with significant pressures on the Health System by the ageing population, creates a significant incentive for state health systems to design and deliver a sustainable solution. Without such action:

“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.”¹¹¹

The Young People in Nursing Homes National Alliance also emphasised that the aged care system has become a default option for health and disability service programs when their service options either lack the capacity to assist further, or they lack expertise (and capacity) to deliver the care provided. Yet the aged care system is under its own pressures and has begun to ‘harden’ its response to people with disability under 65 years of age.¹¹²

Bed blockage: the cost to the patient

People with ABI who remain in institutions for long periods of time become institutionalised in their behaviour and thinking and 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, that 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.¹¹³ 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.

“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.

¹¹¹ Young People in Nursing Homes National Alliance, above n 108, 12.

¹¹² Ibid 9.

¹¹³ Young People in Nursing Homes National Alliance, above n 108.

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.

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 the 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."¹¹⁴

The professional staff who work in these facilities are aware of the limitations of the services they can provide, particularly to those long-stay patients who cannot access funding to move into community-based living. Staffed predominately by health and allied health staff, with models of care focused predominately on a person's health care needs, health facilities can offer little in the way of the support that people need to recover and maintain their daily living skills, communication abilities and participation and integration into the community.

However within their limited resources, many health and allied health care professionals are striving for improvements. The Public Advocate was able to visit and obtain first-hand information about a number of examples of committed health facility staff working to transform the model of care from what has become 'bed-blocked' slow-stream rehabilitation services.

Casuarina Rehabilitation Centre

The Public Advocate visited the Casuarina Rehabilitation Centre at Wynnum to talk to staff there about the recent changes to the model of service at Casuarina Rehabilitation Centre. Like other services of its type, Casuarina Rehabilitation Centre had become a 'destination' for people with ABI.

¹¹⁴ Young People in Nursing Homes National Alliance, above n 108.

Casuarina Rehabilitation Centre (continued)

Rather than maintaining throughput and offering opportunities for people with ABI to transition from acute hospital settings to Casuarina Rehabilitation Centre and receive slow-stream rehabilitation in preparation for transition to the community, Casuarina Rehabilitation Centre had become 'bed blocked' and was a residential service.

Senior staff at Casuarina Rehabilitation Centre began making changes in December 2012 and since then have discharged seven long-stay patients. They have now re-organised the service model so that the new 10-bed unit "Gardenia" operates solely as an in-patient ABI unit utilising a neuro-behavioural approach and goal-centred practice.

New criteria for admission have been developed, one of which is that discharge planning is in place at the time of admission. There is an emphasis on engaging clients in goal setting to encourage their active participation in rehabilitation. When clients are discharged to the community, ongoing outpatient support is provided as they transition to their new residences.

Perhaps one of the most impressive things that was evident to the Public Advocate was the overhaul of the premises at Casuarina Rehabilitation Centre. Staff and clients had worked together to transform the facility by painting walls, finding and moving furniture, and creating art-work. The environment was bright and colourful. There was a new 'shared kitchen' where staff and clients could make coffee and toast together. There were beautiful gardens with vegetable patches and a chicken coop. There were a variety of 'spaces' that had been created so clients could choose whether they wanted a quiet place, a place to watch television, a place to work on the computer, or a place to socialise with others. This had all been done without extra funding.

When the Public Advocate visited, clients were having their lunch in places of their choosing. Some clients were out in the garden watering the plants.

Casuarina Rehabilitation Centre is now working to get more allied health professionals on staff. They have partnered with Griffith University to evaluate and test the efficacy of the new model.

Jacana Acquired Brain Injury Centre (Bracken Ridge)

The Jacana Acquired Brain Injury Centre at Bracken Ridge has also commenced a focus on client-centred goal setting. Using standardised tools, training and education of staff, clients and families, there is a focus on working with clients and their families to identify their short- and long-term goals to motivate and plan their individually-based rehabilitation plan. Referral criteria for the Centre have been developed to emphasise the ability of the person and their family to participate in goal-centred rehabilitation programs and the identification of a preliminary discharge planning process. The staff at Jacana have identified that the centre need not be an 'end point' anymore.

Issues for transition to community-based living

The Public Advocate asked about the issues that should be taken into account to support successful transition from institutional to community-based living, where appropriate and desired.

A coordinated approach

The number one priority for everyone who made submissions to the Public Advocate on this issue was the need for a coordinated approach across systems in response to people with ABI, and improved pathways for people with ABI and their families.

Adults with ABI frequently require support from multiple government and non-government agencies to successfully transition to community-based living and have their ongoing care and support needs adequately met.¹¹⁵ However, a lack of coordination means that people with ABI, their families and organisations have to negotiate access to funding and support across a number of different government agencies to obtain the combination of support, allied health care and accessible accommodation that they need.

Negotiation must occur separately with each individual government department for access to accommodation, support, rehabilitation and medical care. Many commentators spoke about the immense difficulties, frustration, time and resources associated with attempting to coordinate a person's clinical, housing and support services, with key Government departments not 'set up' to accommodate a coordinated response.

There was an identified need to formalise the process for coordinating a person's post acute care pathway. Some have identified the existing Spinal Cord Injuries Response (SCIR), a joint initiative between the Department of Communities, Child Safety and Disability Services and the Department of Health, as a type of model that could be adapted for people with ABI. The SCIR aims to assist individuals with a newly acquired spinal cord injury who are being discharged from the Princess Alexandra Hospital following their acute care and rehabilitation. It provides a

¹¹⁵ QBISM Group, above n 3, 7.

coordinated approach that encompasses a person's health, housing and support needs. There is no such program for people with ABI.

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. 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.

Value of a whole of government coordinated funding approach

The QBISM and Young People in Nursing Homes National Alliance submissions as well as numerous commentators identified a coordinated approach also required a designated whole-of-government coordinated funding approach to this issue.

Early start to discharge planning

The need for discharge planning to begin early in the in-patient process was emphasised by many including the Young People in Nursing Home National Alliance. Along with good links to the local community, early discharge planning can offer the opportunity for programs to begin working with the person to understand their needs, undertake their own assessment processes regarding need and availability of resources, and start planning for the delivery of their 'part' of the joined up response.¹¹⁶

Good connections between health and disability services

Due to advances in medical technology, there is a growing number of people with significant impairments and a range of clinical needs who may be beyond the usual capacity of the existing human services system. It was submitted to the Public Advocate that the development of tightly controlled and separate program areas comprised of health, housing, disability and aged care can result in rigid program boundaries.¹¹⁷

The Young People in Nursing Homes National Alliance stated that one of the central issues for any person with complex health needs is that the health system does not accept responsibility for the ongoing management and oversight of complex 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 support in order to successfully cope with complex health and other support needs. This can have catastrophic results for individuals who may end up in crisis and be re-hospitalised, or alternatively may result in a steady deterioration in the health and wellbeing of clients.

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

¹¹⁶ Young People in Nursing Homes National Alliance, above n 108.

¹¹⁷ Ibid.

The impending National Disability Insurance Scheme

“The Alliance expects that when the National Disability Insurance Scheme... achieves full scheme towards the end of the decade, it will at least provide some funding capacity for this group. The missing part of this picture remains that there is no cross-sector pathway in place to fund the other clinical supports needed. Because this is not a role NDIS will fulfil, there is still no clear way to meet people’s health needs across their life course.”¹¹⁸

Concern was expressed that despite the extra injection of funds that may come with a NDIS, unless systems work together in an integrated way, people with ABI 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.

“It is anticipated that implementation of the National Disability Insurance Scheme (NDIS) from July 2016 will help to improve the supports available to some people with ABI and their families in Queensland. However the NDIS will not fund services ‘more appropriately funded’ through other systems, including rehabilitation and post acute care, housing, employment, education and training services. Collaborative state-wide service planning is therefore required to ensure an integrated systemic response to the needs of the Queenslanders with ABI and their families.”¹¹⁹

Local Protocol developed between Metro North Hospital and Health Service and Disability Services

Sometimes these systems blockages will motivate key personnel at a local level to collaborate and find solutions, as evidenced by the local protocol developed in the Metro North Health and Hospital Services District (MNHHS) between MNHHS and Disability Services (Brisbane and North Coast Regions).

Patients with ABI in Metro North Hospitals were experiencing extensive delays in assessment and processing from Disability Services and, as a result, delays in transition to more appropriate long-term care environments. This led to patients with ABI experiencing long-term stays in acute hospital beds long after they were medically stabilised.

With the aim of improving collaboration between MNHHS and Disability Services, a cross-sector Systems Interface Protocol was developed (Systems Interface Protocol for Adults with Disabilities) to enhance coordination, facilitation and transition points for in-patients with disabilities aged 65 years and under. This protocol articulated an approach to the management of patients referred to Disability Services from MNHHS health facilities. The protocol defines the target patient group and articulates the roles and responsibilities of relevant MNHHS and Disability Services staff in relation to the management and discharge planning for this patient group.

¹¹⁸ Ibid.

¹¹⁹ QBISM Group, above n 3.

Local Protocol developed between Metro North Hospital and Health Service and Disability Services (continued)

The protocol outlines a 5-step process to be followed. This process begins at the point of referral to Disability Services (the point at which patients are entered onto the Adults with Disabilities Pathway); indicates a maximum timeframe for Disability Services assessment; describes a collaborative case conference procedure (that provides a client-centred forum in which to establish and address client needs); outlines the various client discharge pathways that may be explored; and describes a collaborative escalation process (where issues are identified that cause barriers to transition and discharge from hospital that cannot be solved at a local level).

Prior to the Project there was no articulated MNHHS approach to patient management, Disability Services engagement or central data management for this high risk and vulnerable group of patients.

During the Project (October 2012 - June 2013), there were 29 patients discharged from acute or sub-acute care facilities in MNHHS.

Access to rehabilitation services

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.¹²⁰ QBISM stated that despite expertise in acute medical treatment and emergency retrieval in adult ABI rehabilitation in Queensland, there are notable gaps in adult ABI rehabilitation in Queensland.

Numerous stakeholders have submitted that rehabilitation, including different types of rehabilitation, 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. "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."¹²¹

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 at the same location as the patient who is living in the community.¹²²

¹²⁰ Young People in Nursing Homes National Alliance, above n 108; QBISM Group, above n 3.

¹²¹ QBISM Group, above n 3 19.

¹²² Young People in Nursing Homes National Alliance, above n 108, 15.

Victoria's Slow to Recover Acquired Brain Injury Program (STR) does this by delivering rehabilitation 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 rehabilitation 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.

In NSW, a coordinated state-wide network of specialist community-based therapy services has been operating throughout metropolitan and regional areas for the past two decades.

The rehabilitation and therapy a person needs depends on the nature of their injury and their individual needs and different services may be required at different stages in a person's recovery.

It was submitted to the Public Advocate that rehabilitation must also include further access to vocational rehabilitation, as there is good evidence that specialist brain injury programs for vocational rehabilitation are effective in improving return to work outcomes.¹²³

Appropriate support, provided in a flexible way across a person's life course

Many people 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 throughout their lives.

Appropriate and accessible accommodation

For people with ABI, appropriate and accessible housing needs to be available. The QBISM group submission to the Public Advocate stated that:

"There is a need for increased government investment in developing a range of accommodation and support options for adults with brain injury residing in metropolitan, regional and rural areas of the state."¹²⁴

The lack of appropriate accommodation options is one of the main barriers to people 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.

¹²³ QBISM Group, above n 3 14.

¹²⁴ Ibid 10.

While the NDIS may provide many people with the necessary funds to purchase support, appropriate accommodation and housing may not be available. Preparation for this necessary systems response and infrastructure must begin now.

Part 6: What is the Queensland Government doing?

Introduction

This part provides an outline of what Queensland Government has committed to doing to address this issue.

The Department of Health and the Department of Communities, Child Safety and Disability Services (DCCSDS) provided a joint submission (the joint submission) to the Public Advocate in response to the call for submissions on People with Disability in Long-Stay Health Care Facilities. This joint submission provided details of the short-term and medium- to long-term initiatives that will be undertaken by both departments in response to this issue.

The joint submission showed a commitment to and an appreciation of the issue of people with disability in long-stay health facilities.

“Both departments share a mutual concern over people with disability remaining in health facilities owned and operated by the Department of Health for extended periods. This includes people with disability remaining in hospital even though treatment has been completed. It also includes people with disability living in mental health facilities, rehabilitation facilities and long-stay residential facilities. Disability Services and the Department of Health have prepared a joint submission in view of the collaborative initiatives between the departments to reduce the number of people with disability in health facilities.

We recognise the contemporary evidence about the benefits to people living in the community surrounded by their support networks. We also recognise that for some residents who have lived in health facilities for extended periods, the prospect of moving from a facility which offers 24 hour care to the community is very challenging and that some residents or their families may wish their loved one to remain in the facility. It is therefore vital that a person-centred approach is adopted in the transition planning to supported accommodation in the community.

Transition is often very complex and costly, involving a coordinated service response from specialist disability, health and housing departments. Some residents who transition to the community from rehabilitation facilities may continue to require high-level support from allied health services due to complex medical needs and these supports can be beyond what is currently offered through community health provisions.”¹²⁵

¹²⁵ Department of Communities, Child Safety and Disability Services and Department of Health, above n 56.

The Public Advocate provided the Department of Health, DCCSDS, and the Department of Housing and Public Works with an indication of recommendations the Public Advocate would likely make in the final report in response to the issues identified in researching this project and the initiatives identified by the joint submission.

DCCSDS provided a further response on 16 October 2013. Both the joint submission and the further response by DCCSDS are reflected in the description of the identified initiatives on the following pages.

Identified initiatives

Short-term initiatives identified by the Departments of Health and Communities, Child Safety and Disability Services

The joint submission committed to the following short-term initiatives:

Resources

The joint submission and the response by DCCSDS identified that transition from health facilities could be very costly given the high and complex needs of the group of people with disability residing in long-stay health care facilities.

DCCSDS stated that while all identified initiatives would be carried out within existing resources, reference was also made to part of the additional funding of \$868 million announced by the Premier in December 2012 to support the transition to an NDIS being made available to assist people with disability who wish to transition from long-stay facilities into community living arrangements as part of the implementation of the NDIS.

An Action Plan

An Action Plan will be jointly developed by the Department of Health, DCCSDS, and the Department of Housing and Public Works.

This Action Plan will be focused on transition to the NDIS and, as part of this, will consider the needs of people with disability in health care settings and their transition into appropriate accommodation in the community as soon as possible.

DCCSDS also stated that as part of the development of the Action Plan, the department will work together with relevant agencies to identify the most appropriate accommodation options for people with disability currently residing in health care facilities who wish to transition to the community.

In response to the Public Advocate's request for the Action Plan to be made public, DCCSDS state that the Action Plan cannot be released until it is considered by Government in the context of the broader planning for the NDIS.

A timeframe for the public release of the Action Plan was not provided.

Prioritising people with disabilities in health facilities for funding and services within available resources

The joint submission and the response by DCCSDS stated that DCCSDS will continue to provide support to long-stay residents in Queensland Health facilities, to the extent achievable and within 'available resources'.

Local level communication

The joint submission stated that the departments will continue to encourage and provide in-principle support for local level communication and solutions developed between Health and Hospital Services and Disability Services regional offices.

Continuation of the Spinal Cord Injuries Response (SCIR) initiative

The joint submission committed to the continuation of the Spinal Cord Injuries Response (SCIR). SCIR is a coordinated whole-of-government approach to support people with newly acquired spinal cord injuries. The initiative enables eligible people to transition to community living following in-patient rehabilitation in the Spinal Injuries Unit at the Princess Alexandra Hospital. The 2013-14 State Government budget provided \$26.4 million over four years, to support up to 108 people to leave the Princess Alexandra Hospital and return to community living with supports and housing that will accommodate their new support needs.

The Public Advocate considered that people with an acquired brain injury also need a similar coordinated response across key government departments to improve their pathways and access to services.

DCCSDS provided in-principle support for a collaborative and planned approach across government to improve pathways and access to services for people with acquired brain injury.

Considering the needs of long-stay patients in health facilities in the phased approach to the National Disability Insurance Scheme

The joint submission committed to ongoing person-centred transition planning and assessments by both departments to support this group's transition to the NDIS. Queensland's transition to the NDIS will commence on 1 July 2016, and the scheme will be fully implemented by 1 July 2019. By December 2014, Queensland, together with the Commonwealth Government and the NDIS, will have agreed an approach to phasing eligible participants in the scheme. The joint submission stated that this approach to phasing will consider the needs of many groups in the community, including long-stay patients in health facilities.

DCCSDS is committed to considering the 2010 assessments of the people living in Baillie Henderson Hospital by Dr Michael Kendrick in the context of the more current assessment information.

An Audit of all younger people with disability who are long-stay residents in Queensland health facilities

The joint submission committed to a further audit in the second half of 2013 to obtain an up-to-date profile and demographic details to assist planning and preparation for the introduction of the NDIS.

Continuation of the 'Adults with Disabilities Protocol Project'

The joint submission committed to the continuation of the 'Adults with Disabilities Protocol Project' in Brisbane North and the North Coast area. This project, which aims to reduce extended hospital stays for high-risk younger in-patients with disability across the Metro North HHS, was initiated by staff working together at a local level. Protocols were developed that aim to improve coordination and facilitation around transition points for in-patients with disability who have complex needs and who are due to be discharged from hospital.

Continuation of Community Access packages

The joint submission stated that community access packages will be continued at Baillie Henderson Hospital, the Halwyn Centre and Birribi for individuals to participate in community activities within available resources.

Continuation of the Forensic Order (Mental Health Court – Disability) for people with intellectual disability or cognitive impairment

The joint submission identified that where people with an intellectual disability or cognitive impairment subject to a forensic order (Mental Health Court - Disability) are detained to an authorised mental health service under the auspice of the Department of Health, the Director of Forensic Disability will work in partnership with the Director of Mental Health through a Memorandum of Understanding and mirror policies to ensure a coordinated response to client care and support for those who may benefit from disability services.

Planning of the Far North Queensland project

The Far North Queensland project was identified as a key project by the joint submission. This project aims to transition approximately 14 younger people with a disability from hospitals in the Far North Queensland Region. This project, between Disability Services and the Cairns and Hinterland HHS, aims to enhance the capability of services to establish accommodation support for Aboriginal and Torres Strait Islander people with brain injury and associated disabilities. The project will benefit long-term residents transitioning from the Cairns Base Hospital.

Medium- to long-term initiatives identified by the Departments of Health and Communities, Child Safety and Disability Services

The joint submission committed to the following medium- to long-term initiatives:

Full implementation of the National Disability Insurance Scheme (NDIS)

The Queensland Government has committed to full implementation of the NDIS in Queensland in July 2019. A key component in preparing Queensland to transition to the NDIS includes working across departments to understand the needs of people with disability residing in health facilities. Both departments recognise the importance of taking a cross-government approach by including other services areas such as housing in future dialogue and planning for long-stay residents.

A range of suitable housing options including existing social and community housing, new builds and procurements and privately owned or rented properties will need to be considered.

Ongoing person-centred transition planning and assessments to support transition to the National Disability Insurance Scheme

Ongoing person-centred transition planning will occur between both departments for those who have been in health facilities who are likely to require longer term preparation, planning and support to consider alternative options. In past institutional reform processes, work has needed to occur to prepare residents and their families and ensure the availability of accurate information. Take-up of options is often low in initial stages until families see benefits for individuals who have transitioned.

Part 7: The Public Advocate's recommendations for future action by the Queensland Government

Introduction

This Part provides an outline of what the Public Advocate believes is required to ensure that appropriate support is provided for those people with intellectual disability or cognitive impairment who currently reside in long-stay health care facilities. The key recommendations for future action by the Queensland Government are also included in this part of the Report.

The Public Advocate strongly recommends that the Queensland Government make a whole-of-government commitment to improving support for people with disability currently residing in health care facilities. This commitment needs to be funded, prioritised, participatory, individualised and coordinated to ensure appropriate and increasing opportunities for social inclusion and community participation for these vulnerable Queenslanders.

These core principles are further detailed below followed by the key recommendations for further action by the Queensland Government.

Principles

Funded

The current response to pursuing appropriate support for people with intellectual disability or cognitive impairment residing in long-stay health care facilities remains hampered by a fragmented approach that locates primary responsibility for the care and support of these individuals with the Department of Health.

The Public Advocate contends that improving supports and services for people with disability who currently reside in long-stay health care facilities cannot be done without either extra investment and/or a reallocation of existing resources.

Furthermore, the Queensland Government must move away from this fragmented approach and recognise this as a whole-of-government issue, rather than the responsibility of any one department. At least some of the current resources (estimated at \$76.28 million) used to support people in health care facilities should be reallocated to support their needs in more suitable environments and/or to procure supports to change current models of support and improve participation in community, regardless of the department that auspices these arrangements.

Prioritised

Historically this group of people have not been prioritised (evidenced by many people waiting 10-15 years for funding). The low priority accorded to these individuals has been informed by a view that they are currently living in stable accommodation where their care needs are met.

Given that these individuals currently reside in inappropriate accommodation arrangements, do not receive support services congruent with Australia's international human rights obligations, and are at significant risk of deterioration in their health and well being, the Public Advocate contends that these factors should be accorded the highest level of priority.

To ensure an integrated response, the prioritisation of these individuals should occur jointly across all service systems from which an individual may require assistance.

Action to address this issue should be prioritised by Government in a planned and coordinated manner. Reallocating resources in a way that supports more appropriate and integrated service delivery, improved community participation, and transition to community-based living where appropriate and desired should assist with this.

Participatory

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.

Individualised

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 as a collective group without considering the capacities, needs and goals of each person. For example, these individuals are often described as a 'cohort' who have high and complex medical and support needs that require specialist medical support, with suggestions that the support required is not readily available in the community.

Yet evidence suggests that this is not the case for the majority of people with intellectual disability or cognitive impairment residing in long-stay health care facilities. The way in which

support is provided must be responsive to individual need and choice, including a focus on ensuring culturally appropriate responses for Aboriginal and Torres Strait Islander people with disability who reside in long-stay health care facilities.

Coordinated

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.

The development of policy, protocols and/or memorandums of understanding would provide authority for local-level approval to prioritise and allocate resources to individuals, and to coordinate the delivery of services, accommodation and clinical support for these individuals.

Without such authorisation, innovative initiatives that are proposed at the local level can be immensely time and resource consuming with agency staff facing the usual barriers to coordinating support, housing and other services to people. Policies and protocols at the highest levels of the department should support a coordinated approach.

Recommendations

Up-to-date individual assessments for each person with intellectual disability or cognitive impairment residing in a long-stay health facility

There should be an immediate start to the provision of thorough individual assessments by senior clinical staff of the support needs of the entire group of people, with priority given to people who do not have a current assessment (for example those residing in Baillie Henderson Hospital and Halwyn Centre). These assessments should also consider the extent to which a person's support needs could be better met in a community setting.

Individual assessments must be undertaken with each resident with an intellectual disability or cognitive impairment currently residing in long-stay facilities. These residents 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 members of a 'cohort' or 'group' with an assumption that they have the same level of high and complex needs.

Any person who does not have a current assessment, in particular those residing at Baillie Henderson Hospital and Halwyn Centre, must have assessments carried out as a priority. Many have lived in these facilities for significant lengths of time without access to appropriate support to develop their skills and functional capacity, or to ensure their optimal social, emotional and physical well being. The model of care provided in these facilities (where people with disability are segregated from the community) reflects an outdated perspective of disability.

It is 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.

The Public Advocate welcomes the commitment by DCCSDS to undertake individual assessments and, as part of this process, to consider the assessments conducted by Dr Michael Kendrick in 2010 of the people residing in Baillie Henderson Hospital.

These assessments should inform the development of person-centred plans that are developed with the participation of the person and their family. These plans should identify immediate opportunities for access to more appropriate support and community access, as well as, where it is appropriate, begin immediate planning for transition to the community. The Department of Housing and Public Works should be engaged to consider appropriate accommodation options as a priority.

A whole-of-government approach to resourcing and a reallocation of current resources

There needs to be a change to the fragmented way in which resources are allocated across existing portfolios to support these individuals, including a reallocation of existing resources currently used to care for people in health care facilities to support more appropriate models of care and support.

In many respects, despite a commitment to collaboration, the needs of those individuals with intellectual disability or cognitive impairment residing in long-stay health facilities remains the primary responsibility of the Department of Health with the joint submission from the Department of Health and DCCSDS identifying that it cost an estimated \$76.28 million in the 2012-13 financial year to provide services for people with disability under the age of 65 years in the health sector.¹²⁶ Arguably this is significantly more than it would cost to support these individuals in community-based accommodation arrangements.

A recent and similar example of the low efficiency in providing such services in Government-operated facilities was identified by the Queensland Commission of Audit Final Report in relation to Accommodation Support and Respite Services (AS&RS) currently delivered by DCCSDS.¹²⁷ In response to this, the Queensland Government has committed to transitioning all services currently provided by AS&RS to the non-government sector through a formal and transparent recommissioning process that allows for a progressive movement towards client choice and control. This decision has been based on the dual imperatives of both efficiency, and increasing choice and control for clients.

The Public Advocate considers that a similar analysis of the efficiency of delivering disability services in health facilities versus the cost of supporting this same group of individuals in

¹²⁶ Department of Communities, Child Safety and Disability Services and Department of Health, above n 56, 6. This submission noted that the estimate should be used with caution as it is based on a number of assumptions and excludes a number of variables, for example the allied health staff in our community health units who provide therapeutic and maintenance care and organise prescriptions for aids and equipment.

¹²⁷ Queensland Commission of Audit, *Final Report* (February 2013) 3-186.

community-based settings should be undertaken, including consideration for and analysis of the relative benefit to clients across the two settings.

This analysis should inform the development of a coordinated budget bid across the relevant departments to reallocate existing resources and/or provide an appropriate allocation of 'new' resources to support these individuals using more appropriate models of care and/or enable people to transition to alternate community-based arrangements where appropriate and desired.

Action plan to ensure more appropriate support for people with disability residing in long-stay health care facilities

An Action Plan must be developed and implemented to support the transition of people with disability in these environments to appropriate models of support and/or alternate accommodation in the community as soon as possible.

The Public Advocate is adamant that an Action Plan must be developed specifically for this group of people (separate to the Action Plan to transition to the NDIS) to continue the process of deinstitutionalisation in Queensland and transition all people with disability in Queensland to appropriate models of support and/or accommodation.

The Public Advocate considers that this Action Plan should be prioritised for development in 2013-14 and should:

- Be publically available
- Have designated resources
- Designate clear timeframes
- Be informed by consultation with residents, family members of residents and staff in long-stay health care facilities
- Be premised on providing an individualised approach that ensures:
 - people have access to individualised funding with opportunities to self-direct or self-manage their funding
 - people and their families are supported to decide the transitional plan including the type of accommodation and support they prefer
- Identify specific roles and responsibilities for health, disability services, housing and other relevant departments
- Involve planning and implementation at a local level (between health, disability services, housing and other relevant departments) including:
 - development of local protocols aimed at establishing client pathways, case conferencing and coordination of responses to all identified people in long-stay health care facilities
 - participation of individuals and their families in local level coordination

- Involve high level support and coordination at a departmental level (between health, disability services, housing and other relevant departments) including the development of policies and protocols that prioritise this group of people and ensure that different types of support (i.e. housing, support, clinical outpatient care) can be coordinated.

Support local level coordination with high level policy and protocols

Local level coordination should be encouraged, formalised and supported by commitment from the highest levels of the relevant departments to enable authorised and prioritised coordination of services to this group.

The Public Advocate supports the continuation of local level communication, which has led to innovative responses by staff working with counterparts in other departments and to coordinated case planning and review. However this local level coordination requires support and commitment from the highest levels of the relevant departments to allow authorised and prioritised coordination of services to this group.

Policies and protocols must be developed to support local level coordination so that staff working at the local level have appropriate approval to prioritise and allocate resources to these individuals, and to coordinate the delivery of support, accommodation and clinical support.

Without this high level endorsement, local level coordination can be immensely time and resource consuming and individual staff can come up against familiar barriers associated with lack of prioritisation and limited resources being allocated to assist these individuals to access much-needed community supports.

Further investment in a range of accommodation options

The Queensland Government should make further investment in identifying and/or developing a range of appropriate accommodation options to enable people with intellectual disability or cognitive impairment currently residing in health facilities to transition to the community where appropriate and desired.

DCCSDS has indicated that in developing the Action Plan for transition to the NDIS, the department will work with the Department of Housing and Public Works and the Department of Health to identify appropriate accommodation options for people with disability currently residing in health facilities who may be able to transition to community living.

The Public Advocate considers that there must be increased government investment in a range of appropriate accommodation options for people with intellectual disability or cognitive impairment. 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 (including longitudinal research on the outcomes for people who were deinstitutionalised as part of the first wave of deinstitutionalisation) into what provides the best outcomes in terms of social and emotional wellbeing, opportunities for choice, and participation in the community.

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.

This is not to suggest that all 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 once the NDIS commences in Queensland.

Further investment in a range of coordinated rehabilitation services

There must be further investment in a range of rehabilitation services for people with acquired brain injury, including community based rehabilitation. This should not be limited to facility-based rehabilitation but should also be accessible to people living in the community.

Submissions to the Public Advocate indicated that there is currently a paucity of rehabilitation services for people with acquired brain injury in Queensland; this must be addressed.

These rehabilitation services may sometimes be provided in clinical environments but are often more appropriate when provided in situ – where a person is residing in the community. This means the availability of allied health care staff to provide rehabilitative services and other necessary therapy support in the community.

There 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.

Consideration should be given to successful models in other states including the non-facility-based approach utilised by the Victorian Slow to Recover Acquired Brain Injury program.

A coordinated approach to improving pathways for people with acquired brain injury

A coordinated approach for people with acquired brain injury must be developed to improve pathways and access to the current service system.

There is much evidence indicating that people with acquired brain injury need a collaborative and planned response across relevant government departments and non-government agencies to improve their pathways and access to the current service system.

The Public Advocate welcomes the in-principle support from DCCSDS for the development of a collaborative and planned approach across government to improve pathways and access to services for people with ABI.

The Public Advocate considers that a similar response to the Spinal Injuries Response Initiative (SCIR) could be adapted for people with ABI, although not limited to in-patients of a single hospital and with access to community-based coordinators who could link with people with ABI while they are still in-patients to facilitate early discharge planning and connections in the community to the support, accommodation and rehabilitation services they need.

There also needs to be closer links between 'disability services' and 'health services' generally. Traditionally funded and provided separately, along rigid program boundaries, this approach has meant that many people with ABI and significant clinical needs discharged into the disability sector cannot get their health needs met. This can lead to re-institutionalisation. There are similar issues for people with intellectual disability and other medical needs.

Collection of data and information to support culturally appropriate strategies for Indigenous people transitioning back to the community

There must be improvements in the collection of quantitative data and qualitative information on Indigenous people with intellectual disability or cognitive impairment residing in long-stay health care facilities to inform culturally appropriate alternatives to hospital admissions and to increase the success of opportunities for transition back to community living.

The Public Advocate has heard anecdotal evidence that there is a lack of adequate collection of both quantitative data on the numbers of Indigenous people in long-stay health care facilities, and qualitative data in relation to their experience in these facilities and culturally appropriate strategies that support successful transition back to community based living. This includes a lack of information on the negative impacts of prolonged periods of hospitalisation on the individual, their families and communities.

The Public Advocate has committed to working more closely with key government departments and non-government agencies, including those agencies that form part of the

guardianship system to advocate for the better collection of data in relation to Indigenous people with impaired decision making capacity and to better understand the issues for Aboriginal and Torres Strait Islander people with intellectual disability in the current service system in Queensland.

Considering people with disability in long-stay health care facilities in forward planning for the National Disability Insurance Scheme

The needs of this group of people must be considered in the phased approach to the National Disability Insurance Scheme.

The Public Advocate considers that while this group of people must be incorporated into the phased approach for the NDIS, changes to their support arrangements that increase inclusion and participation in the community must not be linked solely to the implementation of NDIS in Queensland and should commence immediately.

The Public Advocate welcomes the commitment given by the Department of Communities, Child Safety and Disability Services to the prioritisation by the Queensland Government of the transition of people with intellectual disability or cognitive impairment who are long-stay residents in health facilities as a priority group for the implementation of the NDIS.

However, as discussed above, the action needed to effect an immediate change to the models of support and accommodation arrangements provided to people with intellectual disability or cognitive impairment who are still living in institutional environments must form the basis of an action plan that is separate to the one that is being developed for the transition to the NDIS.

Given that this group of people are currently living in inappropriate accommodation and not receiving support services congruent with contemporary standards of disability support or Australia's human rights obligations, and that there is a significant risk of deterioration in their health and wellbeing, all people with intellectual disability or cognitive impairment currently living in health care facilities must be prioritised. It is unacceptable to ask all of these individuals to wait for the implementation of the NDIS in Queensland.

Having said that, it is agreed that the Action Plan for transitioning to an NDIS in Queensland must be a priority, and must include consideration for improving systemic pathways for these individuals, including people with acquired brain injury, between health, housing and disability services as well as the development of appropriate accommodation options.

Without the development of systemic pathways and appropriate infrastructure (such as a range of accommodation options) the Public Advocate considers that the ability of this group of people to benefit from the NDIS will be limited.

Conclusion

The investigation underpinning this report was both an enlightening and confronting one for me both professionally and personally.

Despite seeing significant progress in the support provided to people with disability over the 17 years that I worked in the disability service sector prior to commencing in the role of Public Advocate, it saddens me to see that very little has changed over that period of time for those people with intellectual disability or cognitive impairment who remain living in long-stay health facilities.

As an example, I first visited Baillie Henderson Hospital as a university student over 20 years ago and although some of the people who were residing there at that time have had the opportunity to move to community-based accommodation arrangements, there is still a good number who remain.

Most striking about the people who remain living at Baillie Henderson Hospital is the fact that they are no different to those people with disability that I worked directly with in the community early on in my career in disability services. Furthermore, the support needs of these people are, by and large, no more complex than many of those who have had the opportunity to move to community-based support arrangements.

The people living in these facilities are sons, daughters, brothers, sisters, uncles, aunties... and they have family members who care deeply about them and who all have, at minimum, one thing in common – a desire to ensure that their family member is well supported and able to live the best life possible.

Now consider those people with cognitive impairment, in particular those with acquired brain injury. Queensland Health estimates that each year more than 11,000 Queenslanders will acquire a brain injury, of which 4,000 will develop a serious disability.¹²⁸ These are significant statistics and any one of us could find ourselves being counted in those statistics in an instant.

Imagine, just for a moment, that on the way home tonight you or your loved one was involved in a car accident that resulted in catastrophic brain trauma.

How would you feel if you knew that you couldn't access the type of rehabilitation you needed in the place you needed it because the different government departments that were essential to the solution were unable to provide an integrated and timely response. Furthermore, imagine that because of this you were unable to regain the level of functional skill that would have otherwise been possible and, as a result, you were destined to remain stuck in a hospital bed for the rest of your life.

The lack of integrated systems and pathways between and across the relevant Government departments here in Queensland is central to the issues highlighted in this report.

While I respect and value the committed staff who, under the circumstances, are providing the best care that they can for people with intellectual disability or cognitive impairment who are

¹²⁸ Acquired Brain Injury Outreach Service, *What is ABI?* Acquired Brain Injury Outreach Service
<http://www.health.qld.gov.au/abios/asp/what_is_abi.asp>.

residing in long-stay health facilities, this is not enough. As a progressive society, we must acknowledge that the circumstances in which these vulnerable Queenslanders live are unacceptable, and we must respond accordingly.

I urge the current Queensland Government to consider whether this situation should be allowed to continue, or whether government will step in and finally put an end to this practice of institutionalising people with disability in Queensland.

I strongly recommend immediate action that ensures a better future for people with intellectual disability or cognitive impairment who are currently residing in long-stay health facilities in Queensland.



Jodie Cook
Public Advocate

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Appendix 1: Submissions, visits and meetings

Submissions received by the Public Advocate

1. Confidential (family member of person residing in facility) (17 June 2013)
2. Confidential (family member of person residing in facility) (10 July 2013)
3. SEQUEL Association Inc (15 July 2013)
4. Community Visitors (24 July 2013)
5. Community Safeguards Coalition (29 July 2013)
6. BE Lifestyle Retreats (1 August 2013)
7. Confidential (family member of person residing in facility) (2 August 2013)
8. Kim Mortensen, Social Worker, Baillie Henderson Hospital Extended In-patient Service (2 August 2013)
9. Confidential (family member of person residing in facility) (2 August 2013)
10. National Disability Services (NDS) (2 August 2013)
11. Queensland Aged and Disability Advocacy Inc (QADA) (2 August 2013)
12. Community Resource Unit (CRU) (2 August 2013)
13. The Advocacy and Support Centre Inc (TASC) (5 August 2013)
14. Confidential (family member of person residing in facility) (6 August 2013)
15. Baillie Henderson Hospital (Diane Rogers and Shirley Wigan) (8 August 2013)
16. Queensland Law Society (9 August 2013)
17. Queensland Advocacy Inc (QAI) (16 August 2013)
18. Queensland Brain Injury Services Meeting Group (QBISM) (16 August 2013)
19. Young People in Nursing Homes National Alliance (20 August 2013)
20. Metro North Health Service District (21 August 2013)
21. Department of Communities, Child Safety and Disability Services and the Department of Health (Joint Submission) (6 September 2013)

Meetings and visits

1. Meeting with Queensland Advocacy Inc (QAI), Ken Wade and Michelle O'Flynn.
2. Meeting with Ros Harrington, Queensland Brain Injury Services Meeting Group (2 August 2013)
3. Meeting with Metro North Health District: Mary Fenn, Mary Slattery, Roslyn Patterson, Mary Ann Schubert (8 August 2013).

4. Visit to Jacana Acquired Brain Injury Service, Bracken Ridge (22 August 2013)
5. Meeting with staff of Jacana Acquired Brain Injury Service, Bracken Ridge (22 August 2013)
6. Visit to Casuarina Rehabilitation Centre (28 August 2013)
7. Meeting with Dr Ron Hazelton; Cheryl Target; and Sarah Raffell (Casuarina Rehabilitation Centre) (28 August 2013)
8. Meeting with SEQUEL, Danielle Reeves and Kellie Baigent (29 August 2013)
9. Visit to Baillie Henderson Hospital, Toowoomba (10 September 2013)
10. Meeting with Shirley Wigan, Executive Director, Division of Mental Health Darling Downs Hospital and Health Service (10 September 2013)
11. Meeting with Community Visitors, Office of the Adult Guardian (30 September 2013)
12. Meeting with the Queensland Brain Injury Services Meeting Group (8 October 2013)
13. Meeting with Jennifer Cullen, Clare Townsend, Synapse (14 October 2013)
14. Meeting with Michelle O'Flynn, Queensland Advocacy Incorporated, Margaret Deane (14 October 2013)
15. Visit to Halwyn Centre Red Hill (17 October 2013)
16. Meeting with Maree Saunders, Director of Nursing Halwyn Centre Red Hill (17 October 2013)

Appendix 2: Position Statement on Continuing the Deinstitutionalisation of People with Disability in Queensland

June 2013

The Public Advocate supports the right of people with disability to access appropriate support and opposes the placement of people with disability in environments and locations that do not enable inclusion and participation in the community.

The role of the Public Advocate is to protect and promote the rights, autonomy and participation of Queenslanders with impaired decision-making capacity through statutory systems advocacy. I am committed to an evidence-based approach that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for these vulnerable Queenslanders.

Up until the 1980s in Australia, it was common practice for people with disability to reside in large institutions situated on the outskirts of cities. These institutions housed both children and adults with disability in congregate living environments where all day-to-day decisions were made on their behalf by staff. In addition to people with intellectual disability, many people with a physical disability that limited their communication were also institutionalised, often because of erroneous beliefs that they were also cognitively impaired.

The care provided in these institutions was premised on both a medical model of disability, characterising disability as an illness, and a paternalistic approach to people with disability espousing that they were better segregated from the general community to protect themselves and others. There were also many instances of abuse and neglect of people with disability in these institutions.

As a society we have made good progress towards addressing these inequities. Wide-scale movement of people with disability out of large institutions occurred in Australia in the 1980s and 1990s. While outcomes were generally positive, in some instances the lack of sufficient planning inhibited success for some individuals; noting however that there were significant shifts in society's understanding and perception of disability regardless.

The *Convention on the Rights of Persons with Disabilities*¹ has also supported a shift in momentum towards accepting impairment as part of the diversity of our communities. There is increasing emphasis on building the capability of people with disability to maximise their participation in society, as well as increasing the accommodations made by community to meet the needs of people with disability.

In Queensland, many (but not all) institutional living environments have now closed and there has been a concurrent increase in community-based arrangements. However, there are still many people with disability living in 'institutional type' settings and/or who are segregated

¹ *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*').

from the community, often with limited opportunities to increase their autonomy, capability, participation and inclusion.

For example, there are people residing in health care facilities that were originally intended for short-term treatment and rehabilitation, but who remain there indefinitely because of the limited availability of appropriate alternatives.

Additionally, significant numbers of people with intellectual disability or cognitive impairment continue to reside in psychiatric hospitals and other long-stay health care facilities.

Furthermore, the paucity of appropriate services and the limited integration and responsiveness of the Queensland human services system is currently increasing the risk that some service responses, particularly those generated for people with complex support needs, may unwittingly begin to replicate past institutional practices. This is already being evidenced for small numbers of individuals who, often as a result of crises in their lives and a lack of more appropriate options for their support, have over recent years been removed from their community of origin and moved to congregate living arrangements that do not meet their needs and/or locations segregated from community. Many of these arrangements were initially intended as short-term emergency responses, and therefore instigated with little planning, but have unfortunately become longer-term placements.

While the complexity of providing appropriate support for many of these individuals is acknowledged, current funding approaches limit the development of innovative service responses, and the current range of available options is narrow therefore inhibiting choice in relation to where and with whom people should live. Furthermore, there is insufficient emphasis given to individualised planning and support aimed at developing a person's capacity to achieve their maximum physical, social, emotional and intellectual potential.

The Public Advocate supports the right of people with disability to have choice and control over the supports they access in response to their needs.

The Queensland Government must 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. A broader range of options needs to be generated with a focus on individualised planning and flexible responses that promote choice, support existing connections with family, friends and/or community, and strengthen each individual's ability to engage meaningfully with community.

There must be an immediate cessation to the placement of individuals in support arrangements that offer little by way of effective outcomes and do little to support participation and inclusion in the community.

As Public Advocate, I am committed to monitoring this issue, raising awareness about the circumstances of this cohort and to working collaboratively with Government and other key stakeholders to ensure a positive and planned strategy that will provide increased opportunities and effect positive change in the lives of these individuals.

Jodie Cook
Public Advocate

Appendix 3: Project fact sheet: People with disability in long-stay health care facilities

The Public Advocate

The role of the Public Advocate is to protect and promote the rights, autonomy and participation of Queenslanders with impaired decision-making capacity through statutory systems advocacy. We are committed to an evidence-based approach that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for these vulnerable Queenslanders.

Through our systems advocacy work we have become aware that there are a significant number of people with intellectual disability or cognitive impairment who continue to reside in institutional settings including psychiatric hospitals and other long-stay health care facilities. These settings, segregated from the community, are not necessarily optimal environments to promote autonomy, capability, independence and inclusion, or to achieve the best outcomes for these individuals.

Purpose of this project

This project builds on the **Public Advocate's Position Statement on Continuing the Deinstitutionalisation of People with Disability in Queensland** and seeks to raise awareness and promote action by Government with a view to encouraging the development of a positive and planned strategy for this cohort that will increase autonomy and provide enhanced opportunities for participation and inclusion in the community.

What we will do

The Public Advocate has requested information from key government agencies about the number of people with intellectual disability and cognitive impairment who continue to reside in long-stay health care facilities. We are also seeking information on the extent to which key agencies are working together to assess the immediate and future needs of individuals in these facilities; and plan, on an individual basis, for their transition to more appropriate community-based accommodation and support arrangements.

The Public Advocate has also called for submissions on this issue. Views from interested parties are sought on the immediate and future support needs of individuals with intellectual disability or cognitive impairment currently residing in health care facilities and the issues that should be taken into account to:

- assess the appropriateness of pursuing community-based living arrangements;
- increase access to targeted support services that increase community participation and inclusion; and
- support successful transition from institutional to community-based living, where appropriate.

This information will generate a comprehensive evidence base from which the Public Advocate will produce a report detailing the systemic issues and making recommendations for change. This will support the Public Advocate to continue working collaboratively with key agencies to pursue a positive and planned strategy to enable people with intellectual disability and cognitive impairment to live more autonomous lives in the community.

Other publications and resources

The Public Advocate's Position Statement, the call for submissions, and updates about the project and related resources as they become available will be published on the Office of the Public Advocate website at www.publicadvocate.qld.gov.au.

Contact us

For more information about the project, or to contact the Office of the Public Advocate to discuss this issue, please phone 07 3224 7424 or email public.advocate@justice.qld.gov.au

Appendix 4: Call for submissions: People with disability in long-stay health care facilities

What is a submission?

Submissions are your own or an organisation's ideas or opinions about the issue under review. Submissions may be your own personal story that you tell someone or write down, or a written paper about the issue.

Terms of Reference

Your submission should relate to the current issues for people with intellectual disability or cognitive impairment who are residing in health facilities such as hospitals, psychiatric hospitals and rehabilitation services. In particular:

- Whether the support needs of individuals are being met;
- The immediate and future support needs of individuals;
- Whether the support needs of these individuals could be better met in community-based living and the factors that should be considered in making this determination; and
- The issues that should be taken into account to support successful transition from institutional to community-based living, where appropriate.

What will my submission be used for?

Your submission will assist the Office of the Public Advocate to understand the current issues for people with intellectual disability or cognitive impairment who are residing in health facilities such as hospitals, psychiatric hospitals and rehabilitation services. It may be used by the Public Advocate to inform a report on the issue that may be published.

Publication of submissions/confidentiality

The Public Advocate will not publish any of the submissions received, but may refer to the submissions and/or quote information from the submissions in public reports prepared about the issue. The Public Advocate will not publish any information that may personally identify a person with impaired decision-making capacity.

When you make your submission you should indicate whether you want the submission to be public or confidential. **Public submissions** may be referred to in a report published by the Public Advocate and the names of the submitter may be identified. Contact details and addresses will never be published. The issues discussed in **confidential submissions** may be

referred to in reports published by the Public Advocate, but the name of the submitter will not be identified in relation to the issues, or listed in the report.

How to make a submission

Submissions can be made in writing or verbally. There is no particular format you need to follow, but you should address the terms of reference detailed above. Submissions can be made by:

- Email: public.advocate@justice.qld.gov.au
- Fax: 07 3224 7364
- Phone: Please contact us to make a telephone appointment time

The Public Advocate's *Position Statement*, *Project Factsheet*, updates about the project and related resources (as they become available) will be published on the Office of the Public Advocate website at: www.publicadvocate.qld.gov.au.

SUBMISSION DEADLINE 2 AUGUST 2013



Queensland Government

