

# Denial of rights:

the need to improve accommodation and support for people with psychiatric disability

A Special Report to Parliament under s.31 of the *Ombudsman Act 1974* 

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# **Foreword**

This report is about people who live in mental health facilities beyond the point at which they need to be there; and the multiple barriers that prevent them from leaving.

The consequences of this situation are significant – for the individuals themselves, and for the mental health system as a whole. Many people are being denied fundamental rights under mental health and disability legislation, including the right to live in the community and to receive support in the least restrictive environment possible. In addition, people staying longer in mental health facilities than is necessary makes it much harder for those with acute mental illness to get into these facilities to receive the clinical treatment they require.

At the centre of this inquiry is the access of people with mental illness and psychiatric disability to disability services, and the need for Ageing, Disability and Home Care (ADHC) and NSW Health to work more effectively together in providing support. It is unacceptable that these individuals are substantially disadvantaged by inadequate agency cooperation.

As this report illustrates, individuals with psychiatric disability should no longer be excluded from disability services on the basis of their mental illness, or have to remain in hospital as a result of agencies not working together to meet their needs.

The disability sector reforms in NSW, and the planning for the National Disability Insurance Scheme, provide an ideal opportunity for ADHC and Health to improve practice in this area. There must be a genuinely collaborative and person-centred approach to supporting people with psychiatric disability, and a concerted plan for embedding this approach across the disability and mental health sectors.

Bruce Barbour

**Ombudsman** 



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# **Executive Summary**

#### Introduction

The Public Guardian and other stakeholders raised concerns with us about the number of people living in mental health facilities who no longer need to be there.

In response, in June 2011 we commenced an inquiry into this issue. Key elements included:

- reviewing the files of 95 people in 11 mental health facilities across NSW who had been
  identified as being unable to move to the community due to a lack of appropriate and available
  accommodation and support options, or who were admitted to a unit that was considered to be
  inappropriate to their needs; and
- consultation with almost 300 stakeholders, including government and non-government organisations, consumer and carer groups, advocates and peak agencies.

#### File review

## Age, diagnosis, and behaviour

The 95 patients in our review ranged in age from 24 to 82 years; the average age was 49. The vast majority had a psychotic illness – typically schizophrenia or schizoaffective disorder – as well as other conditions, including significant physical health problems, such as obesity and diabetes. Over 60 per cent had a cognitive impairment, including 32 people who had an intellectual disability.

#### Admission information

Over half had been admitted to a mental health facility for between two and 10 years. This included the two youngest people in our review, aged 24 and 25 years, who had been in hospital for over five years. Thirteen people had been in hospital for over 20 years, including two people who had been admitted as teenagers and had remained in hospital for over 40 years.

The vast majority had prior admissions to mental health facilities; almost half had 10 or more admissions.

Over one-third were in secure (locked) or medium-secure units, including 17 people in acute<sup>1</sup> units. The vast majority had been granted leave.

Less than half were involved in rehabilitation activities.

## **Presentation and support needs**

Expert mental health clinicians contracted by our office considered that the majority of the 95 people were clinically well enough to be discharged from hospital, and that all but two people met the criteria for services under the *Disability Services Act 1993* (DSA) in that they:

• had a psychiatric disability<sup>2</sup> that was likely to be permanent;

Acute units are those to which people with acute episodes of mental illness are admitted for treatment. These units comprise the most restrictive form of inpatient accommodation.

We acknowledge that the mental health sector prefers the term 'psychosocial disability' to describe living with a disability that is associated with a severe mental illness. We have used the term 'psychiatric disability' as it is consistent with the *Disability Services Act 1993* and the Productivity Commission's Disability Care and Support inquiry report, both of which we have referenced extensively in this report.

- had functional impairment in one or more areas affecting daily living, including self-care, decision-making, and learning; and
- required ongoing support.

The clinicians advised that three-quarters of the people in our file review had severe, persistent and complex needs that required a high level of support, including ongoing disability support. They were typically considered to require long-term supported accommodation; on-site support and supervision for 16-24 hours per day; a structured living environment; and access to timely and responsive clinical mental health support.

### What we found

NSW mental health and disability legislation and United Nations principles emphasise the right of people with mental illness and psychiatric disability to live in the community and to receive support in the least restrictive environment possible. However, our inquiry has found that many people are staying in mental health facilities beyond the point at which they need to be there.

The conservative estimate is that one-third of people currently living in mental health facilities in NSW could be discharged to the community, if appropriate accommodation and supports were available.

Our inquiry confirmed that the scarcity of appropriate community-based accommodation and support, and the exclusion of people with a primary diagnosis of mental illness from accommodation funded under the DSA, are critical factors affecting the ability of mental health inpatients to move into the community. We also found a number of barriers to discharge within the mental health system.

## Barriers to discharge within the health system

We identified problems with the work undertaken by mental health facility staff to plan for, and facilitate, the discharge of individuals into the community. In particular, we found that:

- no discharge planning had occurred for almost one-third of the people who were considered to be clinically well enough to leave hospital;
- mental health staff in some districts appeared to have limited knowledge of available accommodation and support options, and the eligibility criteria of services and programs;
- the amount and quality of discharge planning was highly variable and, in some cases, appeared to be influenced by factors other than the person's mental health and the availability of community accommodation and support; and
- there were often long periods of time between staff making a referral to a service for accommodation support and following it up; and delays in staff identifying an action to progress discharge planning and carrying it out.

We found that the discharge of patients is also adversely affected by:

- the limitations of the rehabilitation that patients can undertake within the hospital setting;
- the views of mental health staff about the best interests of individual patients, and the views of the patients themselves; and
- the difficulty of transferring patients to less restrictive options in other Local Health Districts.

Our inquiry points to the need for a state-wide review of discharge planning practice in mental health facilities to ensure that:

• practice is in line with relevant policy and legislation;

- decisions regarding support needs and readiness for discharge are informed by recent and accurate information; and
- internal factors adversely affecting discharge are identified and addressed.

#### Barriers to discharge in the community service system

We found that appropriate community supports – including clinical support and long-term and highly supported accommodation – are in short supply, and that this is preventing the discharge of people from hospital.

In addition, our inquiry showed that people in mental health facilities are largely excluded from the accommodation and support that is provided by the disability sector due to their diagnosis and/or location.

#### Availability of clinical mental health support in the community

Many of the people we consulted raised concerns about the availability and adequacy of community mental health support. We were advised that community mental health teams do not currently have the capacity to provide sufficient, and timely, support due to factors such as unfilled mental health positions in some districts, and excessive caseloads.

We were told that the limited capacity of community mental health teams adversely affects discharge planning in mental health facilities – it limits the community team's capacity to accept new referrals, and influences the decisions of mental health facility staff about whether a patient could be appropriately discharged to the community.

Senior mental health staff also expressed concern about people living by themselves in the community who are at risk due to the lack of available clinical support.

## Availability of appropriate community-based accommodation and support

Multiple inquiries since 1983 have repeatedly reported shortages of suitable supported accommodation in the community for people with mental illness – particularly long-term and 24/7 supported housing options. We found that this continues to be a major reason why people remain in mental health facilities longer than necessary.

Our inquiry indicates the need for an increased supply and range of supported housing options that provide on-site support for 16 to 24 hours per day, and for services and support for people with psychiatric disability to be driven by flexible, person-centred and individualised approaches.

We found that the available long-term and highly supported housing options are very limited:

- Across NSW, there are only 114 beds in community residential services operated or funded by the mental health sector that provide 24/7 support.
- This is insufficient to meet existing demand, let alone meet the needs of other people in mental health facilities who could be discharged if appropriate options were available.
- While the Housing and Accommodation Support Initiative (HASI) is an effective model of supported accommodation and agency partnership for people with severe mental illness and associated disability, the number of places is insufficient to meet demand, and it has not typically provided support for more than eight hours per day.
- The disability sector has a much larger number of long-term and highly supported accommodation options, including more than 4,000 beds in ADHC-operated or funded group homes. However, ADHC policy currently excludes people with psychiatric disability who have a primary diagnosis of mental illness from most of this accommodation.

While there is current work underway in the mental health and disability sectors to expand supported accommodation options, it will not resolve the problems identified in our inquiry:

- Health is expanding HASI in NSW to include 48 packages of 16 to 24 hours per day support, over four years. This is a welcome development. However, on its own, it is unlikely to make a significant dent on unmet demand.
- ADHC, via *Stronger Together*, has increased, and is continuing to expand, the number and range of supported accommodation places for people with disabilities. However, an existing ADHC policy exclusion means that the additional places will not typically be available to people with psychiatric disability, even if they meet the criteria of the DSA.

#### Access to accommodation and support under the Disability Services Act 1993

The access of people with psychiatric disability to services and support under the DSA is central to this inquiry.

As a rights-based piece of legislation, the DSA aims to ensure that services are provided to people with disabilities in order to assist them in achieving their maximum potential as members of the community, and to promote increased independence and integration in the community. People who have a disability caused by a psychiatric impairment are included in the target group for services under the DSA.

The Act includes specific reference to people with mental illness and associated disability, indicating that people in mental health facilities are included in the target group, and that the Minister for Disability Services can provide financial assistance to the Minister for Health to enable the funding of psychiatric disability services.

Yet, despite these legislative provisions, people with a primary diagnosis of mental illness and associated disability do not currently have consistent access to the full range of disability services. In particular, they do not have access to the majority of supported accommodation that is funded under the DSA.

This is mainly because ADHC's policy that governs access to this accommodation – the *Allocation of Places in Supported Accommodation* policy – specifically excludes people with a primary diagnosis of mental illness, on the basis that Health is considered to have responsibility for providing this support. The effect of this policy – which appears to be ultra vires – is that these individuals are being excluded from their rights under the DSA.

Our file review found that excluding people with a primary diagnosis of mental illness is highly problematic. In particular, we found that:

- this approach to determining eligibility does not adequately take into account the person's functional impairment and psychiatric disability – the key reason why they need disability services and supports;
- it is not clear how ADHC determines whether mental illness is a person's primary diagnosis, and there is no policy guidance on this critical issue; and
- application of the policy requirements appears to be inconsistent, with some people with psychiatric disability accepted onto ADHC's register for supported accommodation, but not others.

More broadly, the access of people with psychiatric disability to services under the DSA, and to the disability reforms underway in NSW, is currently restricted as a result of demarcations between ADHC and Health, and differing views as to which sector – disability or mental health – has responsibility for providing accommodation and disability support to these individuals.

In this regard, our inquiry supports the position of the Productivity Commission in relation to the proposed National Disability Insurance Scheme (NDIS). In the final report from its Disability Care and Support Inquiry, the Commission contended that clinical mental health care should rest with the mental health sector, and the disability sector (NDIS) should have a role in meeting community-based disability support needs, including accommodation support, for people with significant and enduring psychiatric disability who do not require on-site clinical services.

The Commission's position is consistent with the view advanced by the (then) NSW Government in its submission on the NDIS. Importantly, the Government's submission supported the adoption of an inclusive, coordinated approach in relation to people with psychiatric disability, and emphasised the need for:

- a joint strategy involving the mental health and disability sectors, to build cross-sector capacity and skills and a joint understanding of roles and responsibilities; and
- a collaborative, person-centred approach to planning to determine the sector(s) that best
  meet the identified needs of individuals, and to further determine their respective roles and
  responsibilities.

This position is in line with the ADHC and Health Memorandum of Understanding on the provision of services to people with an intellectual disability and a mental illness. However, this Memorandum only applies to people with these dual diagnoses – there is no agreement between the disability and mental health sectors relating to people with a psychiatric disability who have a primary diagnosis of mental illness.

While we are mindful of the potential resource implications for the disability sector in enabling the access of people with a psychiatric disability to services under the DSA, it is clear from our inquiry that this must occur. The continuing infringement of the rights of these individuals is unacceptable.

In responding to this issue, it will be essential that ADHC and Health work together in building a support system to meet the needs of this vulnerable client group. It will also be important that, as a part of planning for the NDIS, this new system both conforms to the DSA and adopts a person-centred approach.

However, the demarcation between ADHC and Health relating to support for people with psychiatric disability is longstanding, and may not be easily resolved through good leadership and goodwill. It will be important to ensure that implementation of the joint strategy is effectively monitored. If matters relating to cross-agency work cannot be resolved, government may need to consider whether a change to the existing agency clusters would bring mental health and disability closer together.

# **Chapter 1 Introduction**

This report outlines the findings and recommendations of an inquiry we have conducted into the access of people in mental health facilities to accommodation and support services under the *Disability Services Act 1993.* 

The inquiry was initiated under section 11(e) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*, which provides for the Ombudsman 'to inquire, on his own initiative, into matters affecting service providers and visitable services and persons receiving, or eligible to receive, community services or services provided by visitable services'.

## 1.1 Background to the inquiry

Over a number of years, our office has examined the provision by NSW government and non-government agencies of services and support to people with mental illness.

Through our reviewable death, complaint and investigation functions, we have highlighted issues affecting people with mental illness, and have recommended changes to improve the support provided to this group. These recommendations have included improving discharge planning for people who are admitted to mental health services; and enhancing the support provided by NSW Health and Ageing, Disability and Home Care (ADHC) to people with the dual diagnoses of mental illness and intellectual disability.

In November 2009, we tabled a special report to Parliament concerning our investigation into the implementation of the *Joint Guarantee of Service for People with Mental Health Problems and Disorders Living in Aboriginal, Community and Public Housing* (JGOS). The JGOS was an interagency agreement that aimed to coordinate the delivery of services to people with mental health problems and disorders to assist them to maintain their social housing tenancies.

Our report emphasised the importance of secure housing and adequate support for people with mental illness, and noted substantial research that demonstrates that stable housing can result in reduced hospitalisation rates, increased functioning, increased independence, and improved quality of life for people with psychiatric disability arising from mental illness. <sup>3, 4</sup>

However, in our extensive consultations as part of the JGOS investigation, mental health staff told us that a key challenge was the lack of suitable housing options to accommodate people with high needs, particularly transitional and supported accommodation. We were told that beds in mental health facilities were being 'blocked' for periods of up to 12 months because mental health staff could not secure appropriate, supported accommodation for people with the dual diagnoses of mental illness and intellectual disability and/or acquired brain injury.

Overall, our investigation found a range of problems with the implementation of the JGOS interagency agreement, including a lack of consistent effort across government to work collaboratively to provide accommodation and support to people with mental illness.

<sup>3</sup> For example: Reynolds et al, for the Australian Housing and Urban Research Institute, (2002) Effective programme linkages: an examination of current knowledge with a particular emphasis on people with mental illness; O'Brien, et al, for the Australian Housing and Urban Research Institute, (2002) Linkages between housing and support – what is important from the perspective of people living with a mental illness.

We acknowledge that the mental health sector prefers the term 'psychosocial disability' to describe living with a disability that is associated with a severe mental illness. We have used the term 'psychiatric disability' as it is consistent with the *Disability Services Act 1993* and the Productivity Commission's Disability Care and Support inquiry report, both of which we have referenced extensively in this report.

Against this background, in late 2010, the Public Guardian raised concerns with us about the number of people under his guardianship who were staying in mental health facilities despite being clinically well enough to be discharged. The Public Guardian pointed to a lack of community-based and intensively supported accommodation as the key barrier to these patients being discharged, and indicated that a contributing factor is the exclusion of people with a primary diagnosis of mental illness from supported accommodation that is funded under the *Disability Services Act 1993* (DSA).

ADHC's *Allocation of Places in Supported Accommodation* policy (2009) governs the system for obtaining the majority of supported accommodation that is operated or funded by ADHC under the DSA. The policy specifically excludes 'people with a primary diagnosis of mental illness as defined under the *Mental Health Act 2007* for whom the provision of supported accommodation is the responsibility of NSW Health (except where this is provided in accordance with the Boarding House Relocation Program).' The Public Guardian raised concerns with us that this exclusion in ADHC's policy is not consistent with disability legislation, noting that the target group for the provision of disability services under the DSA includes people with psychiatric disability.

In late 2010 and early 2011, we discussed the Public Guardian's concerns with key stakeholders, including NSW Health, ADHC, the Mental Health Review Tribunal (MHRT), and Official Visitors. These consultations informed our decision in June 2011 to commence an inquiry into the access of mental health inpatients to accommodation and support services under the DSA.

#### 1.2 What we did

The scope of this inquiry is broader than access to services under the DSA. To understand the reasons that people with mental illness remain in mental health facilities longer than clinically warranted, we have considered the broader mental health and disability systems, and available community-based and long-term accommodation and support options for people with severe mental illness and associated disability.

The aims of the inquiry are to:

- understand the prevalence and profile of people who live in mental health facilities due to a lack of available community-based accommodation and support services (the client group);
- analyse, from a legislative and policy context, the roles and responsibilities of ADHC and NSW Health in providing services to the client group;
- understand the range of available community-based accommodation and support options provided by ADHC and NSW Health for the client group;
- analyse any blockages and gaps that may be contributing to the continued admission of the client group;
- understand the reasons for the continued admission of the client group in the context of the broader mental health service system; and
- identify potential service models that might improve the support for the client group.

A key part of our inquiry comprised a review of the files of 95 mental health inpatients from 11 mental health facilities across NSW. All of these individuals had been identified by the Public Guardian, the Official Visitors, and/or the MHRT as people who were continuing to live in hospital due to a lack of available community-based accommodation and support options; and/or who were living in a mental health unit that was not appropriate to their needs.

To inform our inquiry, we consulted extensively with almost 300 stakeholders, including government and non-government agencies, consumers and carers groups, advocates and peak agencies. To support the inquiry, we also formed a reference group comprising key stakeholder representatives. (Appendix 2)

# **Chapter 2 The context of the inquiry**

### 2.1 Prevalence of mental illness

Each year, about one in five Australians is affected by a mental illness or disorder. Most are affected by mild to moderate disorders, such as anxiety disorders; affective disorders such as depression; and substance use disorders.<sup>5</sup>

Severe mental illnesses, including psychotic disorders (such as schizophrenia) and severe depression and anxiety disorders, affect a smaller number of people – around one in 200 Australians each year.<sup>6</sup> While the proportion of people affected by severe mental illness is small, the impact can be significant, with the need for many services over a long period. 'Low prevalence' conditions such as schizophrenia and other psychoses account for about 80 per cent of Australia's spending on mental health care.<sup>7</sup>

One-quarter of people with mental illness experience two or more mental health conditions at the same time. In addition, a number of other conditions frequently co-exist with mental illness or disorder, including intellectual disability, organic brain disorders (such as dementia), and alcohol and drug-related problems. For example, a large epidemiological survey of people with intellectual disability found that 40 per cent had major psychopathology.<sup>8</sup>

Research also indicates that people with mental illness are at higher risk of serious health conditions such as diabetes, heart disease, and obesity, due in part to the effects of illness and medication.<sup>9</sup>

## 2.2 Support for people with psychiatric disability

Not all people with mental illness have a disability or require disability support. This inquiry has focused on the criteria of the DSA target group – namely, that the person has a permanent (or likely to be permanent) disability that is attributable to a psychiatric impairment and that results in:

- a significantly reduced capacity in one or more major life activities, such as communication, learning, mobility, decision-making or self-care; and
- the need for support, whether or not of an ongoing nature.

The spectrum of mental health interventions includes promotion, prevention, early intervention, treatment, and continuing care.<sup>10</sup> While all of the interventions are relevant for people with psychiatric disability, it is the treatment and continuing care end of the spectrum – including relapse prevention and long-term care – that is particularly important.

Australian Bureau of Statistics (2007) *National Survey of Mental Health and Wellbeing: Summary of results*. Cat no 4326.0. Data was based on a sample of 8,800 people surveyed.

<sup>6</sup> SANE Australia (2011) People Living with Psychotic Illness: A SANE Response.

Australian Health Ministers (2009) Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009-2014, p16.

<sup>8</sup> Enfield, S L and Tonge, J (1996) 'Population prevalence of psychopathology in children and adolescents with intellectual disability: epidemiological findings', *Journal of Intellectual Disability Research*, 40:2, pp.99–109, cited in *NSW Health (2008) NSW Community Mental Health Strategy 2007-2012: from prevention and early intervention to recovery.* 

<sup>9</sup> Lawrence, D, et al (2001) *Duty of Care – Preventable Physical Illness in People with Mental Illness*, the University of Western Australia; referred to in the National Mental Health Consumer & Carer Forum (2011) *Unravelling Psychosocial Disability* position statement.

<sup>10</sup> NSW Health (2008) NSW Community Mental Health Strategy 2007-2012.

Mental health services, including hospital and community clinicians, have a lead role in delivering mental health care to people with mental illness, including those with psychiatric disability. However, for many people with psychiatric disability, there is also a need for disability support. In this inquiry, we have focused on both the services and supports provided for people with psychiatric disability via the mental health system, and those provided via the disability system.

## 2.2.1 Historical arrangements for disability support

In the past, disability services in NSW were provided by Fifth Schedule Hospitals, serving both people with intellectual disability and people with mental illness. In 1983, the report from the *Inquiry into Health Services for the Psychiatrically III and the Developmentally Disabled* (the 'Richmond Report') recommended the separation of these services and the movement of residents from large institutions into the community.

In 1989, the (then) government transferred responsibility for developmental disability services from the Department of Health to the Department of Community Services.

The NSW *Disability Services Act* was introduced in 1993. The NSW legislation is complementary to the Commonwealth *Disability Services Act* 1986, albeit with a slightly broader definition of the target group. The NSW DSA definition of the target group for services was designed to cover the widest possible ambit of people with disabilities.

Further changes to the agencies responsible for disability services occurred in 1995, with the formation of the Ageing and Disability Department; and in 2001, with the establishment of the Department of Ageing, Disability and Home Care.

To date, responsibility for provision of accommodation and support for people with a primary diagnosis of mental illness (where required), including those with enduring psychiatric disability, has largely remained with NSW Health.

## 2.2.2 Other Australian jurisdictions

The situating of psychiatric disability support in the health sector rather than the disability sector is not unique to NSW. In most of the other Australian jurisdictions, disability services legislation extends to people with psychiatric disability, but responsibility for the provision of services and support rests with the state or territory health agency.

There are two exceptions. In Victoria, the definition of 'disability' in its *Disability Act 2006* does not include psychiatric impairment. In Queensland, in 2007 the state government disability agency assumed primary responsibility for funding and monitoring all mental health programs delivered through non-government organisations (NGOs), including supported accommodation.

# 2.2.3 Clinical rehabilitation versus disability support

NSW Health mental health framework documents<sup>12</sup> distinguish between clinical mental health rehabilitation and disability support for people with psychiatric disability, indicating that:

<sup>11</sup> Fifth Schedule Hospitals were psychiatric facilities providing services to people with a mental illness and people with intellectual disability under Schedule V of the NSW Public Hospitals Act 1929 and the Public Hospitals (Hospitals Incorporation) Amendment Act 1983. Fifth Schedule Hospitals included Allandale; Bloomfield; Collaroy; Cumberland; David Berry; Garrawarra; Gladesville; Grosvenor; Hunter; Kenmore; Lidcombe; Macquarie; Marsden; Morisset; Peat Island; Prison Medical Service; Rozelle; Rydalmere; Stockton; Strickland House; and Tomaree Holiday Lodge.

<sup>12</sup> NSW Health (2002) Framework for Housing and Accommodation Support; and NSW Health (2002) Framework for Rehabilitation for Mental Health.

- clinical rehabilitation interventions are time-limited, and are focused on improvement in functional status, skill development and wellbeing; and
- by contrast, disability support interventions are provided for as long as required, and are focused on the maintenance of functional status, skills, and participation in society.

These policy documents indicate that clinical rehabilitation in NSW should be provided by the specialised mental health sector, and disability support should be provided by NGOs; with both types of support situated in the health sector. However, in reality, while the provision of clinical mental health support in NSW solely rests with the health sector, there are areas of overlap between the health and disability sectors in relation to the provision of disability support – including accommodation support – to people with enduring psychiatric disability.

#### 2.3 The mental health services context

In NSW and nationally, the provision of treatment and support to people with mental illness has increasingly shifted to care in the community rather than in-patient facilities. At the start of the first national mental health strategy in 1992, 29 per cent of mental health spending by states and territories was dedicated to caring for people in the community. By 2007, this had increased to 53 per cent.<sup>13</sup>

Mental health reform is a current area of focus for both the Commonwealth and NSW Governments, with both jurisdictions appointing their first Ministers for Mental Health, and establishing Mental Health Commissions.

#### 2.3.1 National mental health directions and reforms

Historically, state and territory governments have had primary responsibility for mental health services. However, over the past 20 years, the Commonwealth has increased its commitment in this area and set national directions for mental health.

Importantly, the current national strategy<sup>14</sup> focuses on a whole-of-government approach to mental health reform, including coordination between agencies responsible for housing, disability services, family services, education, and workforce training and development. Of relevance to our inquiry, the strategy includes the development of appropriate clinically supported short-term and long-stay accommodation options for people with severe or ongoing disability caused by mental illness.

One-quarter of the \$2.2 billion package for mental health reform in the 2011/12 Federal Budget is committed to improving outcomes for people with severe and debilitating mental illness. Most of these funds are for the Partners in Recovery Initiative, to establish Support Facilitators who will provide a single point of contact for people with severe and persistent mental illness and their families; deliver flexible care packages to meet all of the person's care needs; and coordinate the provision of care across various agencies.

At its April 2012 meeting, the Council of Australian Governments (COAG) signed a \$201.3 million National Partnership Agreement on Mental Health to address known gaps in state services, such as accommodation support. The agreement includes funding for NSW over five years for:

• the expansion of the Housing and Support Initiative (HASI) to include support for 16 to 24 hours per day (\$35.2m); and

<sup>13</sup> Australian Health Ministers (2009) Fourth national mental health plan: an agenda for collaborative government action in mental health 2009–2014.

<sup>14</sup> The current national strategy comprises the COAG *National Action Plan on Mental Health 2006-2011*; the National Mental Health Policy; and the *Fourth National Mental Health Plan 2009-2014*.

• in-reach support services for boarding house residents assessed as having mental health issues, through low-level support packages (\$10.2m).

In January 2012, the federal government established a National Mental Health Commission, which will monitor and evaluate the national mental health system and provide policy advice to government; and released a draft *Ten Year Roadmap for National Mental Health Reform* for consultation. Longterm actions identified in the draft Roadmap, include increasing access to various levels of stable accommodation to assist people with severe and persistent mental illness and complex care needs; and improving coordination and integration between mental health and other services, including housing and disability services.

#### 2.3.2 The NSW mental health system

#### Legislation

The provision of care, treatment and control of people with mental illness or disorder in NSW is governed by the *Mental Health Act 2007*. Consistent with United Nations principles, the Act emphasises that care and treatment is to be designed to assist people, wherever possible, to live, work and participate in the community; and is to be provided in the least restrictive environment possible, with the minimum restriction to liberty.

Notably, the Act stipulates that, at reviews, the Mental Health Review Tribunal must order the continued detention in a mental health facility of an involuntary patient if the Tribunal determines that a patient is a mentally ill person and 'no other care of a less restrictive kind, that is consistent with safe and effective care, is appropriate and reasonably available to the patient.' <sup>15</sup> Appendix 3 provides a summary of provisions relevant to this inquiry.

## Policy directions and reform

In 2002, NSW Health released two frameworks<sup>16</sup> to provide direction to government and non-government mental health and other services in the provision of housing and accommodation support and rehabilitation for people with mental illness.

The Framework for Housing and Accommodation Support emphasised that people with psychiatric-related disability require non-discriminatory access to disability support services. It also indicated the need to establish formal collaborative partnerships between housing, clinical and accommodation support services to enable this to occur. Importantly, the framework indicated that:

- comprehensive policies and procedures, in line with the DSA, would be 'essential for all housing and accommodation support services for people with mental health problems';<sup>17</sup> and
- key partners in the development of housing and accommodation support options for people with mental illness included non-government disability services and ADHC.

The HASI model is based on the *Framework for Housing and Accommodation Support*. However, we note that these two elements of the framework have not been adopted in that model.<sup>18</sup>

<sup>15</sup> Mental Health Act 2007, section 38(4).

<sup>16</sup> The Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders, and the Framework for Rehabilitation for Mental Health.

<sup>17</sup> NSW Health (2002) Framework for Housing and Accommodation Support, p.21.

<sup>18</sup> While the HASI Resource Manual (2006) refers to a HASI needs assessment being in accordance with the Disability Services Standards relating to service access, no other reference is made to the disability legislation or standards.

In 2005, the NSW Government released two five-year companion plans that detailed its whole-of-government approach to improving care for people with mental illness and the state's contribution to the COAG action plan:

- *NSW: A New Direction for Mental Health* detailed funding commitments of almost \$1 billion, including increased funding for community-based mental health services; capital works to open additional inpatient beds; and the provision of additional HASI support packages.<sup>19</sup>
- The NSW Interagency Action Plan for Better Mental Health included a focus on improving outcomes for people with severe mental illness and those with complex needs. A priority strategy in the plan was to 'explore options for expanding residential rehabilitation and supported accommodation for people with very high support needs'.

The NSW Community Mental Health Strategy 2007-2012 outlines the directions for community mental health services in NSW over five years. It indicates that HASI 'will provide the full range of levels of psychosocial rehabilitation accommodation support', with expansion to include 'HASI in the Home'.

The above plans have ended. Further strategic planning relating to mental health services in NSW is expected to occur following the establishment of the NSW Mental Health Commission on 1 August 2012. Core functions of the Commission include planning and delivering strategic direction for mental health in NSW; ensuring that services are appropriately designed and targeted; and reviewing, monitoring, and reporting on how the funds are being used.

Other key roles of the Commission involve reviewing, evaluating and reporting on mental health services (as well as other services and programs provided to people with mental illness, and other issues affecting people with mental illness).

#### Current interagency agreements

Other important interagency agreements involving Health and ADHC that are of relevance to this inquiry are:

- The Memorandum of Understanding and Guidelines between ADHC and NSW Health in the Provision of Services to People with an Intellectual Disability and a Mental Illness ('ADHC/Health MOU' November 2010) commits the two agencies to work in cooperation to provide coordinated care to people with mental illness and intellectual disability, including people with 'low cognitive functioning'. It requires the development of joint forums and protocols in each Local Health District <sup>20</sup> (LHD) to facilitate local arrangements for providing services including discussion of cases that require joint agency management; and identification and resolution of broader issues, such as gaps in service provision.
- The Housing and Mental Health Agreement (November 2011) between the Departments
  of Health and Family and Community Services (including ADHC) replaces the JGOS. The
  Agreement focuses on providing coordinated, collaborative and flexible interagency support
  for people with mental illness who are homeless, at risk of homelessness, or in social housing.
  It is aligned to, and consistent with, the ADHC/Health MOU.

#### Mental health services in NSW

Mental health services in NSW are mainly delivered through public mental health facilities or community mental health services. LHDs also directly provide, or fund NGOs to provide, specialist supported accommodation services and rehabilitation programs.

<sup>19</sup> In 2005, 460 lower support packages were released. Between 2005 and 2007, a further 226 high support packages were released across NSW.

<sup>20</sup> In January 2011, and consistent with the *National Health and Hospitals Network Agreement*, 15 Local Health Districts and three speciality networks replaced eight larger Area Health Services.

All mental health services are expected to comply with the National Mental Health Standards. All LHD-operated services also undergo accreditation by the Australian Council on Health Care Standards against the EQuIP5 clinical framework.

In 2010/11, there were 2,762 funded mental health beds in NSW, of which 1,098 were non-acute beds.<sup>21</sup> Average availability of the beds was 93 per cent and average occupancy was 85 per cent. That is, there were approximately 2,348 total beds, including 933 non-acute beds, occupied at any one time during the year.

In comparison with other Australian jurisdictions, in June 2008, NSW:

- exceeded the national average in the provision of in-patient beds (34.9 beds per 100,000 population compared with the national average of 30.8 beds);
- exceeded the national average in the provision of supported places in public housing (21.8 places per 100,000 population compared with the national average of 18.2 places); and
- was below the national average in the provision of community-based residential accommodation <sup>22</sup> (1.9 community residential beds staffed 24 hours per day per 100,000 population compared with the national average of 7.4 beds).

In NSW, the number of supported places in public housing has progressively increased, while the number of community-based residential beds staffed 24 hours per day has declined, reflecting the growth of the HASI program as the preferred model of supported accommodation. The number of supported places in public housing grew from 987 in 2003 to 1,516 in 2008. The number of general adult community residential beds staffed on a 24-hour per day basis declined from 171 in 1992/93, to 124 in 2008.<sup>23</sup>

#### Community residential services

The definition of a 'Community Residential Service' that NSW Health reports against is:

'a service that is considered by the state, territory or commonwealth funding authorities as a service that:

- has the workforce capacity to provide specialised mental health services; and
- employs suitably trained mental health staff to provide rehabilitation, treatment or extended care on-site:
  - to consumers residing on an overnight basis;
  - in a domestic-like environment; and
- encourages the consumer to take responsibility for their daily living activities.

These services include those that employ mental health trained staff on-site 24 hours per day and other services with less intensive staffing (but the trained staff must be on site for a minimum of 6 hours a day and at least 50 hours per week).'24

'Suitably trained mental health staff' can include individuals with Vocational Education and Training qualifications in community services, mental health, or disability sectors; and those with experience in mental health or disability relevant to providing mental health consumers with appropriate support.<sup>25</sup>

<sup>21</sup> NSW Health (2011) Annual Report 2010-2011.

<sup>22</sup> Includes general adult, child and adolescent, older persons, and forensic community residential beds.

<sup>23</sup> Department of Health and Ageing (2010) National Mental Health Report 2010.

<sup>24</sup> Ministry of Health advice, 20 February 2012, citing definition outlined in METeOR, the Metadata Online Registry.

<sup>25</sup> Ministry of Health advice, 20 February 2012.

At 30 June 2008, NSW was reported to have had 321 beds that met the definition of community residential services (comprising general adult and older persons community residential services), including 131 beds staffed on a 24/7 basis, and 190 beds staffed less than 24 hours.<sup>26</sup>

At the time of our inquiry, NSW Health was not able to tell us the number or location of the community residential beds provided or funded by its LHDs to deliver 24/7 support, and indicated that we would need to obtain this directly from the districts. As indicated in Table 1, information provided by all LHDs for our inquiry indicates that there are currently 160 beds across NSW that meet the definition of community residential services, comprising 114 beds staffed on site on a 24/7 basis; and 46 beds staffed on site for less than 24 hours but at least 50 hours per week and six hours per day.

Table 1: Number of beds in community residential services in NSW, by Local Health District

Local Health District	Number of beds in community residential services				
	24/7 LHD	24/7 NGO	>50hpw/ 6hpd LHD	>50hpw/ 6hpd NGO	Total beds
Central Coast	0	0	0	0	0
Far West NSW	0	0	0	0	0
Hunter New England	0	0	0	0	0
Illawarra Shoalhaven	10	0	0	0	10
Mid North Coast	0	6	0	0	6
Murrumbidgee	0	0	0	0	0
Nepean Blue Mountains	0	0	0	6	6
Northern NSW	0	12	0	6	18
Northern Sydney	19	0	7	0	26
South Eastern Sydney	0	0	0	0	0
South Western Sydney	0	0	0	0	0
Southern NSW	0	0	0	0	0
Sydney	0	0	0	0	0
Western NSW	19	0	17	0	36
Western Sydney	4227	6	10 <sup>28</sup>	0	58
Total	90	24	34	12	160

Between 2008 and 2012, there appears to have been a substantial decline in the reported numbers of community residential beds. The numbers provided by the LHDs indicate a reduction of 17 beds staffed on-site 24/7, and 144 beds staffed at least 50 hours per week/ six hours per day. It is unclear whether the discrepancies in the numbers of beds are due to different interpretations by the districts of the definition of community residential services, or due to a real decline in the number of places.

Numerous Health documents indicate that the provision of supported accommodation should sit with NGOs. However, this has not consistently occurred across NSW. Of the 160 places, three-quarters (124) are operated by LHDs, and support is provided by clinical mental health staff. All of the NGO-operated places (36) are supported by non-clinical staff.

Most of the community residential accommodation places (114) provide 24/7 on-site support.

Over 40 per cent of these places (48) are targeted at, or currently only house, specific populations.

<sup>26</sup> Department of Health and Ageing (2010) National Mental Health Report 2010.

<sup>27</sup> Western Sydney LHD also advised of 130 inpatient beds in Cumberland Hospital rehabilitation wards and cottages – all of which are staffed 24/7. While reporting against Community Residential Services can include those located within hospitals, we have not included these beds in the count as the other LHDs did not include inpatient beds, and our focus is on community-based options.

<sup>28</sup> Includes two beds that are currently closed due to staff maternity leave.

This includes 19 places for people aged 65 years and above; 13 places for women only; a 10-bed residence that currently only accommodates men; and six places for women with dependent children.

The amount of support provided to people in the 46 community residential service places providing less than 24/7 on-site support varies. All provide support for at least 50 hours per week/ six hours per day, but some of the places include support for up to nine hours per day, with on-call support available outside of these hours. Six of the 46 places are specifically targeted at young men aged up to 25 years.

Community residential services include a mix of group home, hostel, and cluster unit accommodation. The number of places per residence (or cluster) varies from five to 29 beds.

Information provided by the LHDs indicates that:

- The distribution of community residential services across NSW is uneven. Less than half (7) of the 15 LHDs have community residential services; only six LHDs include accommodation staffed on a 24/7 basis.
- The provision of LHD-operated versus NGO community residential services varies widely
  across the districts. Three of the districts have LHD-operated services only; three have NGO
  services beds only; and one has both services.
- Many of the community residential places are intended to be transitional accommodation, with the goal of independent living in the community in social or private housing.
- Demand for community residential places tends to outstrip supply. All but four of the currently operating community residential services were reported to have no vacancies.
- Four LHDs had closed 32 beds in residences providing support for at least 50 hours per week/ six hours per day, for reasons that included a lack of funds to undertake OH&S repairs of the residence. Two LHDs had closed premises (19 beds) in order to review the accommodation model and the needs of their districts following low occupancy levels.

#### The Housing and Accommodation Support Initiative (HASI)

The HASI program has become the main supported accommodation model for people with mental illness in NSW. Over the past 10 years, NSW Government responses to recommendations and plans aimed at increasing the range and availability of supported accommodation options have focused overwhelmingly on HASI.

HASI is a major partnership program, jointly funded by NSW Health and Housing NSW, to promote recovery of people with mental illness by providing access to stable housing linked to specialist clinical and accommodation support. It is a three-way partnership, with housing stock provided and managed by public or community housing providers; clinical support provided through community mental health teams; and accommodation support and rehabilitation services associated with psychiatric disability provided by NGOs.

HASI is targeted at people with a moderate to severe level of psychiatric disability, who are capable of benefiting from the provision of disability support services. Accommodation is available long term, with an expectation that support needs will reduce over time. The program provides varying levels of disability support, ranging from five hours per week (Low HASI), to a maximum of eight hours per day (Very High HASI).

Since its introduction in 2002, the program has expanded in stages to include new models, including HASI in the Home, which provides a low or medium level of support for people who have their own home and are not eligible for social housing; and a HASI model designed for Aboriginal people, which comprises 100 low, medium and high packages.

As at July 2011, 1,135 HASI places were available. As indicated in Table 2, the vast majority of HASI packages provide five hours of non-clinical support per day (High HASI) or less. Very High HASI comprises four per cent of available HASI packages.

Table 2: HASI support providers, by HASI types

Organisation	Low	High	Very High	In Home	Aboriginal
Aftercare	47	9	4	7	4
Mission Australia	67	14	0	15	15
Neami	100	75	26	37	6
New Horizons	77	76	8	53	23
On Track	10	1	0	0	10
PRA	57	27	0	49	8
Richmond Fellowship NSW	46	88	4	32	34
St Luke's	0	8	0	11	0
Uniting Care	37	17	8	25	0
Total	441	315	50	229	100

HASI has been independently evaluated, and found, overall, to deliver positive outcomes for participants in terms of housing stability, reduced number of hospital admissions, increased community involvement, and better physical and mental health.<sup>29</sup>

Information from the COAG meeting in April 2012 indicates that the National Partnership Agreement for Mental Health incorporates \$35.2 million to fund the expansion of HASI in NSW to include 48 packages providing 16–24 hour support.

## Other outreach or drop-in support

In response to our request to all LHDs for details of the community residential services they operate or fund (excluding HASI), districts provided information about a range of places that involve staff support on-site for less than 50 hours per week/ six hours per day. The information related to outreach or drop-in support that is provided in 13 LHDs to approximately 655 people in Health, Housing NSW, or community housing-owned properties, or their own homes.

LHDs provide drop-in support to 282 places (43%); NGOs to 227 places (35%), and both LHDs and NGOs provide drop-in support to 146 places (22%). The majority of the individuals receiving drop-in support (443) live in social housing owned by Housing NSW or community housing organisations.

The information provided by the LHDs related to a range of support models and levels. Some of the individuals receive clinical support only, with Assertive Outreach Teams providing medication supervision twice a day. Others receive the equivalent of a HASI package, with partnerships between housing, mental health, and NGO disability providers. Some of the places have access to on-call staff support on a 24/7 basis. Many are intended as transitional support.

Four LHDs indicated that they operate step-up and/or step-down accommodation (42 places in total). This includes NGOs in two LHDs that have used surplus HASI funds to deliver temporary step-down accommodation support for 25 people leaving mental health facilities to transition to the community. Both services have indicated that these support models will cease by mid-2012 as the surplus funds have been expended.

LHDs reported 62 vacancies in the drop-in support places, across 11 of the 13 districts that offer this support. Reported reasons for some of the vacancies included the service deliberately keeping

<sup>29</sup> University of NSW Social Policy Research Centre (2011) Evaluation of the Mental Health Housing and Accommodation Support Initiative (HASI), Second Report.

some beds unfilled due to the small size of the houses; and delayed referral processing due to the Christmas holiday period.

In addition to the places reported to us by the LHDs, there are other clinical drop-in supports available to people with mental illness in NSW living in private accommodation or social housing, including clinical outreach provided by mental health services such as Assertive Outreach Teams.

#### Other mental health support

Outside of clinical services, the mental health sector also funds community-based supports for people with severe mental illness. These include NGO services aimed at assisting individuals to engage in social, recreational and vocational opportunities in the community, and to access the services they need. Community supports include the NSW Health-funded Recovery and Resource Services;<sup>30</sup> and the Commonwealth-funded Personal Helpers and Mentors Scheme,<sup>31</sup> and Support for Day to Day Living Program.<sup>32</sup>

## 2.4 The disability services context

## 2.4.1 Disability policy directions and reform

Significant reforms regarding support for people with disabilities are planned at the national level and are currently underway in NSW.

The model for a National Disability Insurance Scheme (NDIS) that has been proposed by the Productivity Commission, and supported by COAG, includes people with psychiatric disability. The Commission determined that 'the NDIS should meet the community support needs of people under the pension age who have significant and enduring psychiatric disabilities and who have scope to be supported in the general community.'33 Under the proposed NDIS, people with psychiatric disability will be eligible to apply for assessment for individual funding packages to meet their disability support needs.

The current focus in NSW is on enhancing a person-centred approach to the provision of services to people with disabilities, providing options for individualised funding, and developing innovative models of support. The second phase of *Stronger Together* – the NSW Government's 10-year plan for reforming disability services – provides impetus for the development of person-centred and self-directed funding initiatives for people with disabilities. Under *Stronger Together 2* (ST2), individualised funding arrangements will be available from 2011/12, and anyone receiving disability services will have the option of using an individualised and portable funding arrangement by the end of 2013/14.

Of relevance to this inquiry, ST2 also includes:

- Expansion and reconfiguration of supported accommodation options to provide more flexibility
  and a continued focus on building life skills and community participation. Funding commitments
  include 1,750 new supported accommodation places over five years, bringing the total to 7,500
  places by 2016.
- The closure by 2017/18 of all ADHC-operated or funded large residential centres, and the transition of residents to community-based accommodation.

<sup>30</sup> Recovery and Resource Services aim to provide improved access to community social, leisure and recreational opportunities and vocational services.

<sup>31</sup> The Personal Helpers and Mentors Scheme (PHaMS) provides funding to non-government organisations to engage personal helpers and mentors to assist people with severe mental illness and complex care needs who are living in the community to better manage their activities.

<sup>32</sup> The Support for Day to Day Living Program aims to improve the quality of life of individuals with severe and persistent mental illness through the provision of structured and socially based day programs delivered by non-government organisations.

<sup>33</sup> Productivity Commission (2011) Final report of the Inquiry into Disability Care and Support, p. 27.

## 2.4.2 The NSW disability services system

### Legislation

The *Disability Services Act 1993* (DSA) provides for the funding and delivery of disability services, and sets out the standards that must be applied in the design, administration and delivery of services to people with disabilities.

The legislation aims to ensure that services are provided to people with disabilities that help them to achieve their maximum potential as members of the community and to achieve positive outcomes, such as increased independence, employment opportunities, and integration in the community. Key principles are that people with disabilities have the same basic human rights as other members of Australian society, and that these rights apply irrespective of the nature, origin, type, or degree of disability.

Section 5 of the DSA defines the target group for disability services and support, which includes people with a disability caused by a psychiatric impairment:

- (1) For the purposes of this Act, a person is in the target group if the person has a disability (however arising and whether or not of a chronic episodic nature):
  - (a) that is attributable to an intellectual, psychiatric, sensory, physical or like impairment or to a combination of such impairments, and
  - (b) that is permanent or is likely to be permanent, and
  - (c) that results in:
    - (i) a significantly reduced capacity in one or more major life activities, such as communication, learning, mobility, decision-making or self-care, and
    - (ii) the need for support, whether or not of an ongoing nature.<sup>34</sup>

At the time of its introduction, the NSW Parliament noted that the legislation improved on the *Commonwealth Disability Services Act 1986* definition of a person in the target group for services, in order to cover the widest possible ambit of people with disabilities. Parliament noted that definitions of disability in the Commonwealth DSA had resulted in the denial of services to certain persons with disabilities, and that the inclusion of 'however arising' in the definition of the target group for the NSW DSA would 'ensure that such persons are not selectively excluded from coverage and thereby also excluded from access to services.'<sup>35</sup>

The DSA includes specific reference to people with mental illness and associated disability:

- Section 5.2 states that a person is in the target group if they are an involuntary patient; forensic patient; under detention in a mental health facility; or subject to a community treatment order but only if the services provided for their care are not inconsistent with the *Mental Health Act 2007*.
- Section 12A provides for the Minister for Disability Services to provide financial assistance to the Minister for Health to enable the funding of psychiatric disability services. The Act indicates that services funded under this section are taken to be 'designated services' for the purposes of the legislation. As such, any services funded by the Minister for Health under this section would need to conform to the principles and application of the principles of the DSA.

Funding under the DSA is conditional on services complying with the objects, principles, and applications of principles set out in the Act, as reflected in the Disability Services Standards. All

<sup>34</sup> Disability Services Act 1993, section 5(1).

<sup>35</sup> Second reading speech for Disability Services Bill, NSW Legislative Assembly, 11 March 1993.

disability services funded under the DSA are required to implement the standards and meet practice requirements outlined in ADHC's *Standards in Action* manual.

In 2008, the Australian Government ratified the United Nations *Convention on the Rights of Persons with Disabilities*. The Convention includes obligations to ensure that people with disabilities are able to live in the community; are not obliged to live in a particular living arrangement; and have access to a range of in-home, residential and other community support services to support living and inclusion in the community.<sup>36</sup> The Convention includes people with 'long term mental impairments' and Australia is bound to give effect to its provisions in domestic law and policy.

#### **Disability services in NSW**

In NSW, specialist disability services are primarily provided by ADHC and the NGOs it funds. Services include:

- supported accommodation;
- · respite;
- in-home support, including Home and Community Care (HACC) services and intensive personal care services;
- community engagement programs, including skills development and day programs;
- · case management, therapy services, and behaviour support; and
- information and advocacy services.

#### Eligibility and access

To be eligible for ADHC-operated services, a person must have an intellectual disability<sup>37</sup> or multiple disabilities where intellectual disability is also present. The same criterion does not apply to the non-government disability services that ADHC funds. Many of the NGOs funded by ADHC specialise in providing support to people with other disabilities, including mental illness, cerebral palsy, physical disability, acquired brain injury, and sensory disability.

Access to disability services is not straightforward. There are multiple services providing multiple programs, with varying eligibility criteria and intake processes. There is currently no 'one door' across NSW that people with disabilities can approach to obtain services and supports.

For access to ADHC services, applicants typically must go through ADHC's regional Information, Referral and Intake (IRI) teams. These teams are designed to provide information and advice; assess applicants for eligibility for ADHC services; and make referrals to other services as appropriate. The IRI teams provide the most central means for people with disabilities to obtain information about what disability supports are available and appropriate to meet their needs.

Access to the disability services funded by ADHC depends on the type of support being sought. For many community-based supports, access can be via direct contact with the service, or by referral via the IRI teams. For supported accommodation, all applicants must go through ADHC's IRI teams.

<sup>36</sup> United Nations Convention on the Rights of Persons with Disabilities, adopted December 2006, ratified by Australia July 2008, Article 19.

<sup>37</sup> To meet the definition of intellectual disability in the policy, the person must have intellectual functioning measured at two or more standard deviations below the mean for the Full-Scale score on a recognised test of intelligence (IQ70 and below); and significant deficits in adaptive functioning in two or more areas; and these deficits in cognitive and adaptive functioning are manifest before 18 years. Alternatively, the person must have a specific diagnosis of a syndrome strongly associated with significant intellectual disability made in a written report by a health professional or Diagnostic and Assessment Service.

#### Policy and guidelines

ADHC's Intake and Prioritisation and Allocation policies and the ADHC/Health MOU outline the process for accessing ADHC services. In relation to mental health inpatients, the MOU indicates that mental health staff are to call the ADHC Regional IRI team as close to the time of admission as possible; and ADHC staff are to assess whether the situation requires an immediate response, and allocate a case manager as a high priority. The MOU states that situations requiring an immediate response include homelessness, and that this would include people 'inappropriately occupying a respite or mental health bed'.38

The Allocation of Places in Supported Accommodation policy ('Allocation policy') relates to certain supported accommodation places in both ADHC-operated and funded non-government disability services. All requests for supported accommodation must be made by an ADHC or NGO case manager, via contact with ADHC's IRI teams. Where eligible for supported accommodation, the person is notified in writing that their request has been added to the Register of Requests for Supported Accommodation.

To be eligible for accommodation under this policy, a person must have a disability as defined by the DSA, and have a support needs assessment that indicates the appropriateness of supported accommodation. Excluded from eligibility under the policy are children under the age of 16 and/ or under the care of the Minister for Community Services, and 'people with a primary diagnosis of mental illness as defined under the Mental Health Act 2007 for whom the provision of supported accommodation is the responsibility of NSW Health (except where this is provided in accordance with the Boarding House Relocation Program)'.39

The Allocation policy does not apply to all models of disability accommodation or support, or to all accommodation-related programs. It does not include large residences, licensed boarding houses, in-home support services, or emergency supported accommodation arrangements.

#### Access to supported accommodation covered by ADHC's Allocation policy

ADHC operates and funds a range of supported accommodation services under a number of different programs. Across the programs, a variety of supported accommodation types are available, including:

- group homes, village and cluster models, villas, apartments and co-located services (up to 24/7 support); and
- in-home support services including drop-in support and flexible packages.

Most of the supported accommodation provided or funded by ADHC comes under its Community Living Program. In 2010/11, approximately 7,800 people accessed Community Living support from ADHC-operated and funded organisations.<sup>40</sup>

The Allocation policy applies to 'group accommodation' provided under this program. In 2010/11, 4,154 people accessed group home support provided by ADHC and NGOs. Over one-quarter of the people living in these group homes (1,112) had a primary or secondary psychiatric disability. Of these, six per cent (268) had a primary psychiatric disability.<sup>41</sup>

<sup>38</sup> NSW Health (2010) Memorandum of Understanding and Guidelines between ADHC and NSW Health in the Provision of Services to People with an Intellectual Disability and a Mental Illness, p.17.

<sup>39</sup> Department of Family and Community Services, Ageing Disability and Home Care (June 2009) Allocation of Places in Supported Accommodation policy and procedures, p.7.

<sup>40</sup> Department of Family and Community Services Ageing, Disability and Home Care (2011) Achievements Report 2010/11, p.35. Community Living support includes group home accommodation; drop-in support; Boarding House Relocation Program accommodation and services; Leaving Care accommodation and services; and Community Justice Program accommodation.

<sup>41</sup> ADHC advice, 5 April 2012.

As at 30 June 2011, there were 2,087 people on ADHC's register of requests for supported accommodation, comprising 710 people with an immediate need for accommodation, and 1,377 with future needs. Seventy-three people on the register (3%) had a primary psychiatric disability, most of whom (43) had been identified as having an immediate need for supported accommodation.

ADHC has advised that 11 of the 73 people with a primary diagnosis of psychiatric disability on the register for supported accommodation currently live in mental health facilities.

#### Access to supported accommodation not covered by ADHC's Allocation policy

Access to a range of other disability accommodation and supports is via separate intake and allocation processes. This includes drop-in accommodation support, the Community Justice Program (CJP), the Younger People in Residential Aged Care Program (YPIRAC), and the Integrated Services Project (ISP). Appendix 4 provides details about access to these programs.

People with a primary diagnosis of mental illness who are living in mental health facilities are largely unable to access supported accommodation under these programs because they do not meet the eligibility criteria, or because available places are very limited. For example:

- The CJP requires an individual to be in custody and to have an intellectual disability that meets ADHC's criteria.
- The YPIRAC prioritises people younger than 50 years who are living permanently in residential aged care.
- People with an acquired brain injury are eligible for Disability Housing and Support Initiative (DHASI) drop-in support, but there are only 50 places and the program is currently at full capacity.
- People with mental illness and/or psychiatric disability can be eligible for the ISP, but capacity is limited to around 24 people per year, and there are other eligibility criteria that must be met to gain access.

#### Licensed boarding houses and the Boarding House Relocation Program

The *Allocation* policy indicates that, while Health has responsibility for providing supported accommodation to people with a primary diagnosis of mental illness, the exception to this is accommodation provided under the Boarding House Relocation Program – where ADHC has responsibility.

In NSW, boarding houses are required to be licensed if they accommodate two or more people with disabilities who require support. The majority of people living in licensed boarding houses have a mental illness that requires ongoing treatment and support. A review in 2010 found that 67 per cent of licensed boarding house residents in NSW had a psychiatric disability; 19 per cent had an intellectual disability; and eight per cent had alcohol-related brain damage.<sup>42</sup> Many residents also have considerable physical health concerns, including chronic problems such as emphysema, ischaemic heart disease, diabetes, obesity, and hypertension.<sup>43</sup>

ADHC has lead responsibility for administering and implementing the Boarding House Relocation Program, which provides services to residents who need to relocate due to increased support needs or closures. Services under the program are quarantined, to ensure that capacity in the program is maintained state-wide, and to prevent people displaced from licensed boarding houses from

<sup>42</sup> Department of Family and Community Services Ageing Disability and Home Care (2010) *Evaluation of Primary and Secondary Health Care Services Project.* 

<sup>43</sup> NSW Ombudsman (2011) More than board and lodging: the need for boarding house reform, special report to Parliament.

becoming homeless. The majority of services funded by ADHC under the program include a range of supported accommodation service models, including group homes and drop-in support services.

To be eligible for the Boarding House Relocation Program, a person must have a disability as defined under the DSA; have resided in a licensed boarding house in NSW for at least six months of the previous year; and have had an assessment that identifies that they are no longer eligible for entry to a licensed boarding house.

#### Large residential centres

Over 1,500 people with disabilities currently live in residential centres operated by ADHC or NGOs. Residential centres are congregate models of accommodation, housing between seven and 20 people (small residential centres) or more than 20 people (large residential centres) on one site. Under ST2, the NSW Government has committed to closing all residential centres by 2017/18. There is a 'no admissions' policy in place for existing residential centres, with the only exception being emergency admissions approved by the Minister or ADHC Chief Executive; these must have an exit plan.

In 2010/11, over one-quarter of the people living in ADHC-operated or funded residential centres (438) had a primary or secondary psychiatric disability. The vast majority (379) had a secondary psychiatric disability, including almost one-third of those living in ADHC-operated centres (333). Four per cent of people living in disability residential centres (59) had a primary psychiatric disability; over half of whom (34) lived in NGO-operated centres accommodating ex-licensed boarding house residents. 44

#### Other community-based disability accommodation and support

The disability sector funds a range of other community-based supports for people with disabilities. including in-home personal care and other supports, such as those under the Attendant Care program and the HACC program. The Attendant Care program provides flexible and individualised support to around 880 people with a physical disability and/or who need personal help to complete daily living activities. Attendant Care support is typically available for 15 to 50 hours per week.

The HACC program is jointly funded by the Commonwealth and state/territory governments to provide support to people with moderate, severe, or profound disability and their carers under the Home and Community Care Act 1985 – not the DSA. The program helps people to remain at home and prevent inappropriate or premature admission to residential care. Eligibility for services is based on the level of functional disability that makes it difficult to perform the tasks of daily living without help or supervision. Individuals can currently access HACC services via multiple avenues, including direct contact with providers.

Under ST2, the disability services system has started to include flexible funding packages to support individuals and their families to develop models of accommodation and support that suit their needs. The Supported Living Fund provides \$50,000 per person to enable people with disabilities to live in their own home with a mix of informal and paid supports. Individual Accommodation Support Packages provide tailor-made packages for people with medium to very high accommodation support needs, but who do not require 24/7 support. To be eligible, individuals must have a disability defined by the DSA, and have a needs assessment that indicates that supported accommodation is appropriate.

<sup>44</sup> ADHC advice, 5 April 2012.

# Chapter 3 File review: what we found

## 3.1 Sample selection

The Public Guardian, Official Visitors, and the MHRT initially advised our office of 145 patients of mental health facilities whose situations they believed warranted review because the individuals were:

- unable to be discharged due to a lack of appropriate community-based accommodation and support; and/or
- living in a mental health unit that was not appropriate to their needs.<sup>45</sup>

From this group, we selected a sample of 95 patients that provided a geographic spread across NSW and included those in both stand-alone psychiatric hospitals and in units in general hospitals. Forensic and private hospitals and patients were not included in the scope of this project.

As shown in Table 3, the files of patients in 11 public mental health facilities were reviewed.

Table 3: Number of patients by Local Health District and mental health facility

Local Health District	Mental health facility	No. patients
Northern Sydney	Macquarie Hospital	25
Western Sydney	Cumberland Hospital	24
Southern NSW	Kenmore Hospital	11
Sydney	Concord Centre for Mental Health	9
Illawarra/Shoalhaven	Shellharbour/ Wollongong Hospitals*	7
Hunter/New England	Morisset Hospital	6
Western NSW	Orange Hospital (formerly Bloomfield)	4
South West Sydney	Liverpool Hospital	3
Northern NSW	Lismore Hospital	3
South East Sydney	Prince of Wales Hospital	3
Total		

<sup>\*</sup> One patient was in Wollongong Hospital and six were in Shellharbour Hospital.

Four of these facilities are stand-alone specialist psychiatric hospitals (Macquarie, Morisset, Cumberland and Kenmore); the other seven are co-located with general hospitals.

# 3.2 Review process

We reviewed the MHRT and NSW Health mental health files of individuals<sup>46</sup> using a data collection tool that we developed with advice from members of our Inquiry Reference Group.

We also met representatives of treating teams (including consultant psychiatrists, nurse unit managers, occupational therapists, and social workers), as well as mental health directors and senior managers. The meetings enabled us to clarify information about individuals, and to discuss broader issues affecting the client group – including barriers to discharge, the availability of community accommodation and support options in various locations, and the effectiveness of work between relevant agencies and stakeholders.

<sup>45</sup> Information was provided to us in response to a requirement to provide a statement of information, pursuant to section 18 of the *Ombudsman Act 1974*.

<sup>46</sup> Nine patients did not have an MHRT file, so in those cases we only reviewed the NSW Health file.

To inform our review, we sought additional data about the 95 patients from NSW Health's data analysis unit, InforMH.<sup>47</sup> We also contracted two psychiatrists to provide expert clinical advice in relation to the 95 people.<sup>48</sup> The expert clinicians reviewed our data and the InforMH data to provide an opinion as to:

- · whether the individual was clinically well enough to be discharged;
- the degree of complexity of the person's needs and the likely level of support required; and
- whether the person met the criteria for the target group of the DSA.

In December 2011, we sought updated information from NSW Health regarding the patients who had been discharged either during our review or shortly afterwards. At the same time, we sought information from ADHC about any contact by that agency with the 95 patients.

# 3.3 Characteristics of patients and admission details

#### 3.3.1 Patient demographics

The sample of 95 people comprised:

- 45 women and 50 men;
- 35 people from a culturally and linguistically diverse background, of whom six preferred to speak a language other than English; and
- four Aboriginal people.

The age range of the people in our file review was from 24 to 82 years. The average age was 49 years.

Table 4: Number of people by age group

Age group (years)	Number	Percent rounded
24 – 34	14	15
35 – 44	23	24
45 – 54	23	24
55 – 64	21	22
65+	14	15
Total	95	100

## 3.3.2 Admission history and duration of admission

The vast majority (91) had experienced prior admissions to mental health facilities. Most had multiple admissions, and almost half had 10 or more previous admissions.

<sup>47</sup> InforMH provided demographic information, legal status, admission data such as length of stay, previous number of admissions, total days of admission across all stays, and the most recent Health of the Nation Outcome Scores (HoNOS) and Life Skills Profile scores (LSP), extracted on 29 September 2011.

<sup>48</sup> Associate Professor John Basson, seconded from Justice Health/Forensic Mental Health Network to the UNSW Department of Developmental Disability Neuropsychiatry, Consultant Forensic Psychiatrist in Sydney West Local Health District; and Dr Keith Johnson, a research fellow with UNSW Department of Developmental Disability Neuropsychiatry.

Table 5: Number of prior mental health admissions

No. of prior admissions	No. of patients
Zero	4 <sup>49</sup>
1 to 5	27
6 to 9	20
10 to 19	29
20 to 29	7
30+	8

Source: NSW Health InforMH, data extracted 29 September 2011

Some patients had moved between mental health facilities. If no discharge to the community had occurred between transfers, we regarded this as one continuous admission. The duration of continuous admission for the 83 patients who were still admitted at the time of our review is shown in the table below.

Table 6: Duration of continuous admission, still admitted patients

Admission duration (yrs)	No. patients
Up to 1yr	3
1yr up to 2yrs	10
2yrs up to 5yrs	29
5yrs up to 10yrs	20
10yrs up to 15yrs	7
15yrs up to 20 yrs	3
20yrs +	11
Total	83

Almost half of these individuals (41) had been in hospital for over five years. The 11 people who had been in hospital for over 20 years included a man who had been admitted for 53 years – since he was 17; a man who had been admitted for 47 years; and a woman who had been admitted for 43 years – since she was 16.

Three people in our file review had been admitted for less than one year. Each of the three individuals had experienced many previous admissions.

Table 7 shows the age groups of the 83 people who were still admitted at the time of our review, and the duration of their continuous admission. We found that, while older patients tended to have experienced a longer stay, four people aged 24-34 had been in hospital for between five and 10 years. This cohort included two people aged 24 and 25 who had been in hospital for around five and a half years.

<sup>49</sup> InforMH data indicated that four patients had no prior admissions. However, our file review did show evidence of previous admissions for these individuals. The number of prior admissions was recorded for three of the four people, and ranged from two to 12 previous admissions.

Table 7: Age group by duration of continuous admission, still admitted patients

Age	Admission duration (years)							
group (years)	up to 1yr	1yr up to 2yrs	2yrs up to 5yrs	5yrs up to 10yrs	10yrs up to 15yrs	15yrs up to 20 yrs	20 yrs +	Total
24- 34	2	1	6	4	0	0	0	13
35-44	0	5	8	4	1	1	0	19
45-54	0	2	6	7	2	2	1	20
55-64	1	2	6	2	3	0	7	21
65+	0	0	3	3	1	0	3	10
Total		10	29	20			11	83

Twelve patients had been discharged by the time of our file review. The duration of their admission is shown in the table below.

Table 8: Duration of continuous admission, discharged patients

Duration of admission (yrs)	No. of patients
Up to 1yr	2
1yr up to 2yrs	2
2yrs up to 5yrs	2
5yrs up to 10yrs	3
10yrs up to 15yrs	1
15yrs up to 20 yrs	0
20 yrs +	2
Total	12

Like those patients who were still admitted, the two people discharged within a year of admission had previously experienced many mental health admissions. At the other end of the spectrum, one of the patients who had been discharged had lived in hospital for almost 43 years, and another had been an inpatient for almost 54 years. Both of these individuals were discharged to aged care facilities.

## 3.3.3 Mental Health Review Tribunal reviews, legal status and advocacy

## Legal status, quardianship and financial management

The majority (73) were involuntary patients at the time of their most recent MHRT review. Twenty-two people were voluntary patients.

Forty people in our file review were under quardianship, most (35) with the Public Guardian. Of the 22 voluntary patients, 17 were under quardianship, mainly the Public Guardian (14). The majority of people in our file review (72) were under formal financial management.

#### Information for MHRT reviews

The types of reports provided by mental health staff to the MHRT, and the quality of the information contained in the reports, varied across the facilities. It was not always clear to us what had informed the reports by mental health staff, particularly views regarding the need for individuals to only be discharged to 24/7 support.

We found that the MHRT hearings did not consistently prompt mental health staff to conduct a current assessment of the person to inform the treating team's opinion about the individual's readiness for discharge. We identified reports that were largely unchanged over a number of years, including repeated references to the same behaviour incidents.

For 18 people in our file review, information relating to the MHRT hearings reported that the individuals did not need continued mental health admission but could not be discharged as there was no less restrictive accommodation available in the community to meet their needs.

## Legal and non-legal advocacy

Most of the people in our file review (68) did not appear to have legal representation at their last MHRT hearing. This included two-thirds (49) of the involuntary patients, and the vast majority (19) of the voluntary patients.<sup>50</sup>

Nine people in our file review appeared to have the involvement of a disability advocate or the lay advocate from the Mental Health Advocacy Service. A Member of Parliament had also been involved in relation to one of these individuals.

## 3.3.4 Diagnoses and co-morbidities

All but one of the people in our file review had a current diagnosis of a psychotic illness. The most common diagnoses were schizophrenia (71) and schizoaffective disorder (23). One person had a history of bi-polar disorder, but was not considered by mental health staff to have a current mental illness.

As indicated in Table 9, the vast majority of patients (93) had a mental illness diagnosis and one or more co-morbid conditions (that is, they had another mental illness, disability or other condition, in addition to their main mental illness diagnosis). Only two patients had a single mental illness and no co-morbid conditions indicated on their file.

Table	Q-	Co-m	orbid	condit	tions <sup>51</sup>

Category	Co-morbid condition	No. patients
Physical conditions, disabilities	Physical health issues	72
	Physical disability	8
	Sensory disability	4
Intellectual disability and other cognitive	Intellectual disability	32
impairments or neurological disorders	Other cognitive impairment	20
	Neurological disorders	12
	Organic mental disorder	1
Drug and alcohol disorders	Drug and alcohol disorder	20
Major mental illnesses	Mood disorders	13
	Schizo-affective disorder	4
	Schizophrenia	1
	Bi-polar disorder	1
Other disorders	Attention-deficit hyperactivity disorder	6
	Personality disorder	5
	Behavioural disorder	3

<sup>50</sup> NSW Legal Aid policy indicates that involuntary patients are eligible to receive legally-aided legal representation for MHRT initial inquiries and for reviews up to 12 months after admission. Although involuntary patients are eligible for legally-aided representation beyond 12 months, it is only provided if they request it, or if they appeal against their continued detention and their application for legal aid meets the means, merit and availability of funds test applied by Legal Aid.

Physical disability includes cerebral palsy and hand contractures; Sensory disability includes blindness, vision impairment, deafness and hearing impairment; we recorded individuals as having an Intellectual disability where this was specifically stated on their file; Neurological conditions include acquired brain injury, Motor Neurone Disease, Multiple Sclerosis, Muscular Dystrophy and Huntington's Disease; Organic mental disorders are mental disturbances resulting from temporary or permanent brain dysfunction caused by organic factors such as alcohol, metabolic disorders and ageing; Mood disorders include depression and anxiety; Behavioural disorders include socially inappropriate behaviours, such as spitting and kicking, violence and aggression.

While one-third of the people in our file review were recorded as having an intellectual disability, over 60 per cent had some degree of cognitive impairment (58 people).

Three-quarters had considerable physical health issues, including obesity (25); diabetes (24); hypertension (13); incontinence; gastro-oesophageal reflux disease; high cholesterol; respiratory conditions, including asthma, chronic obstructive pulmonary disease, and sleep apnoea; and risks relating to falls and choking.

Sixteen of the 93 people with co-morbid conditions had a single mental illness and physical health issues, with no other conditions.

The people with drug and/or alcohol disorder tended to be in the younger age groups. Each of the four people aged 24 or 25 years, and one-third of the people aged 26 to 44 years (11), had a drug and/or alcohol disorder.

#### 3.3.5 Behaviours

Sexually aggressive behaviour

Criminal involvement, convictions

Mental health staff had recorded a range of behaviours demonstrated by individuals in our file review that they considered to be 'challenging'; that placed the person or others at risk; and/or that required management, such as supervision, accommodation in a secure unit, or restriction of leave. Some of the behaviours were current at the time of our review; while others were documented as having previously been of concern but were not current.

Table 10 shows the different types of behaviours that had been identified by mental health staff in relation to the people in our file review.

Table 10. Denaviours, previous and current, by the number of patients		
Behaviour	Previous (No. of patients)	Current (No. of patients)
Non-compliance with medication	57	29
Aggressive behaviour, violence	67	26
Threatening, intimidating behaviour	37	26
Absconding	31	12
Sexually inappropriate behaviour	14	11
Sexual disinhibition	14	11
Damage to property	14	6
Drug misuse	32	1
Alcohol misuse	22	1
Suicide attempts	15	1
Self-harm	14	1

Table 10. Rehaviours, previous and current, by the number of nationts

Two-thirds of the people in our file review (65) demonstrated current behaviour that was considered to be challenging. Non-compliance with medication was the most frequently recorded current behaviour, affecting almost one-third. Aggressive or violent behaviour and threatening or intimidating behaviours were the next most frequently reported current issues. Just over half of the people with current challenging behaviour (36) displayed three or more behaviours, and 14 people had two behaviours of current concern.

2

20

Forty-one people had other behaviours not included in the list above, including spitting, intrusiveness, urinating in public, and impulsive or excessive eating.

Almost a third of the people in our file review (30) were recorded as having no current challenging behaviours.

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#### 3.3.6 Current presentation

Our expert clinicians reviewed the information that we had recorded about individuals' current presentation, together with the InforMH data, in order to assess each person's readiness for discharge, disability and impairment, and the complexity of the individual's needs. The clinicians assessed that:

- The vast majority of the people in our file review (82) may be clinically well enough to be discharged from hospital.<sup>52</sup>
- All 95 individuals had a disability that was attributable to a psychiatric impairment or a combination of impairments. For all but two people, the clinicians assessed that the disability was permanent or was likely to be so.
- All had impairment in one or more domains affecting daily living, including decision-making, self-care, communication, learning, and mobility. Self-care and decision-making were the most common areas of functional impairment.
- All required ongoing support.

The expert clinicians provided an opinion on the complexity of each person's needs. Their opinion of complexity took into account factors such as the person's mental state and response to treatment; existing co-morbid conditions, functional impairments and challenging behaviours; complicating factors such as institutionalisation and patient or family opposition to discharge; and past experience of community living.

#### **Complex needs**

The clinicians advised that the vast majority of the people in our file review (74) had severe, persistent and complex needs requiring a high level of support. These individuals typically had a severe mental illness and enduring psychiatric disability, required prompting and/or assistance with all or most activities of daily living; had co-presenting conditions such as cognitive impairment, physical health problems, and/or drug and alcohol disorder; and had challenging and/or impulsive behaviours that required support, such as aggression.

Many of these individuals had been identified as no longer requiring or benefiting from clinical rehabilitation – this included people whose functioning was identified as being too low for effective clinical rehabilitation, and others who had reached their maximum level of improvement in that environment. All were noted to need ongoing disability support.

File information and expert clinician advice indicated that the people with complex needs in our review typically required:

- long-term or permanent supported accommodation;
- on-site support and supervision for 16-24 hours per day;
- · a structured living environment; and
- access to timely and responsive clinical mental health support.

Seven of the 74 people with complex presentations had been discharged.

<sup>52</sup> The clinicians advised that there was insufficient baseline information in relation to one patient to determine whether he was clinically well enough to be discharged. We have included this man in the 'well enough for discharge' group as records indicated that staff had been undertaking recent discharge planning.

## Case study 1

A 55-year-old man living in a mental health extended care unit as an involuntary patient had been in hospital for almost five years at the time of our review. He has chronic treatmentresistant schizophrenia, characterised by persecutory, grandiose and religious delusions. He experiences auditory hallucinations, responds to unseen stimuli, and is recorded as having no insight into his illness.

The man has a range of physical health concerns, including insulin dependent diabetes, chronic liver disease, and hepatitis C. He requires high-level supervision and assistance with daily living activities, including self-care, nutritional intake, and medication. His management and understanding of diabetes is noted to be poor, and mental health staff consider that he would be at high risk of not taking his medication and mismanaging his diabetes, with potentially serious consequences, if he was discharged without adequate community support.

Prior to his current admission, the man had been discharged to his own home with a Community Treatment Order. He had daily community mental health team visits, nursing support, and Home Care involvement, but was unable to manage living independently despite that support.

Our expert clinicians assessed that the man may be clinically well enough to be discharged, he has high support needs, and that his mental state is unlikely to improve further. They indicated that he would need accommodation support for 16-24 hours per day in the community. There was no indication that any discharge planning had occurred.

The expert clinicians identified three people with very complex needs who would be likely to require intensive and potentially restrictive accommodation options to be successfully supported in the community. These individuals tended to have treatment-resistant mental illness with multiple other disorders (including personality disorder and cognitive impairment), and very difficult behaviours and current risks (including inappropriate sexual behaviour, damage to property, drug use, and noncompliance with medication and programs).

Our clinicians assessed that one of the three was not yet well enough to be discharged from hospital; and that the others required very intensive support and containment in the community to prevent relapse and risk of harm to themselves or others.

## Not complex needs

The expert clinicians assessed that the support needs of 18 people were not particularly complex. Overall, the mental state of these individuals was stable or able to be reasonably managed; they took medication as required; had reasonable skills in carrying out daily living activities (although required prompting and/or supervision); and their behaviour needs were being effectively managed. Five of the 18 people had been discharged.

Many were noted to be appropriate for (or had already been discharged to) existing HASI packages, placement with family, or licensed boarding houses. However, low complexity in terms of need did not always mean low support. Some were noted by the clinicians as requiring high level ongoing support in a structured living environment.

## Case study 2

A 46-year-old man living in a mental health rehabilitation unit had been in hospital for over 11 years at the time of our review. He has schizophrenia and a mild intellectual disability, and is a voluntary patient via the substitute consent of the Public Guardian.

The man has a history of substance abuse, criminal behaviour and aggression, but no recent activity of this kind. His mental state is stable, and he has frequent leave to attend a work program and to stay with family on weekends. The man has difficulties learning and naming objects, some speech difficulties, and requires assistance but minimal prompting with daily living activities.

The man's mother, advocate, Public Guardian and a Member of Parliament have all been involved in advocating for him to be discharged to long-term supported accommodation in the community, and mental health staff have held complex case conferences with all parties and ADHC to progress discharge planning. Our expert clinicians assessed that the man would thrive in a structured environment.

Subsequent to our review, the man was discharged to an ADHC group home.

## 3.3.7 Types and security of units

The people in our file review were admitted to high dependency, acute, rehabilitation, and extended care units.

**Acute** units are those to which people with acute episodes of mental illness are admitted for treatment when their care cannot be managed in the community or in a less restrictive unit in a mental health facility. **High dependency** acute units are used for the treatment and care of patients with intensive needs or who need close supervision.

The average length of stay in acute units is reported to be less than 21 days. These units comprise the most restrictive form of inpatient accommodation. Mental health staff told us that acute and high dependency units are usually secure, although some patients may be allowed leave.

Non-acute units in mental health facilities include rehabilitation and extended care units. **Rehabilitation** units focus on intervention to reduce functional impairments that limit the independence of patients. They are characterised by an expectation of improvement over the short to mid-term. **Extended** care is defined as care for one year or longer.

The table below shows the type of unit in which individuals were living at the time of our review, or immediately prior to their discharge.

Table 11: Type of unit for admitted and discharged patients

	Type of unit	No. of patients still admitted	No. of patients discharged	Total
Acute	High dependency	2	0	
	Acute	11	4	15
Non-acute	Rehabilitation	19	1	20
	Extended care	51	7	58
Total		83	12	95

Thirteen people still admitted at the time of our file review were in acute units. Six of these individuals had spent the whole of their admission in an acute unit: three people for less than one year, and three people for between one and two years. We note that rehabilitation units are not available in every mental health facility, and we were told that many rehabilitation units have beds in short supply, making it difficult to move patients out of acute units.

In our file reviews, we found that acute units were sometimes used as a means to stabilise people who had experienced an escalation of symptoms, and to provide increased structure and supervision to manage a particular behaviour, such as absconding.

More than half of the people in non-acute units had been in hospital for five years or more. This included over 60 per cent of those still admitted patients who were in rehabilitation units (12), and 28 of the 51 still admitted people who were in extended care units.

Non-acute units are often 'open', or unlocked, allowing patients some freedom of movement in the grounds of the mental health facility. However, this is not the case for all such units. Nineteen of the people in our file review were admitted to secure or medium-secure rehabilitation or extended care units.

Of the 13 people assessed by our expert clinicians as not clinically well enough to be discharged, three were in acute units; two were in rehabilitation units; and eight were in extended care units.

## 3.3.8 Leave arrangements

NSW Health's Discharge Planning for Adult Mental Health Inpatient Services policy recognises the importance of day, overnight and/or weekend leave in assisting a consumer's reconnection to the community, particularly for those who have had lengthy periods of hospitalisation.

We found that that the vast majority of people in our file review (83) had been granted leave. Most (78) had been granted day leave, and 38 people had been granted overnight and/or weekend leave.

One-third (32) had been granted unescorted leave. This included individuals who spent several nights a week in their own home or the home of a family member, and others who were on trial placements in licensed boarding houses, group homes or aged care facilities.

Five people in our file review had not been granted any leave. They had a range of active symptoms or challenging behaviours, including two people who were considered by staff to be at high risk of absconding. One of the five people who had not been granted any leave had been discharged to an aged care facility by the time of our review.53

<sup>53</sup> For another five people, it was not clear from the file information whether they had been granted leave.

## 3.3.9 Programs and activities

We found that the vast majority of the people in our file review (84) accessed activities or programs while admitted to the mental health facility; mainly social activities.

- Three-quarters (71) had involvement in social activities, such as on-site bingo, tai chi, music, art, crafts, movie nights, gym, gardening, bus trips, and escorted holidays.
- Fewer than half (44) accessed rehabilitation activities, including on-site and off-site day centres, cooking, and shopping trips.
- One-quarter (25) attended work or education activities, including off-site attendance at TAFE and supported employment.

Thirteen of the 84 people were noted to be involved in activities intermittently or reluctantly.

Nine people did not appear to have engaged in any activities or programs. Reasons for the lack of involvement of these individuals included continuing positive or negative symptoms and/or aggressive behaviour, physical ill-health, and individual choice. Two of the nine people have since been discharged.

Table 12: Type of unit by number of patients participating in activities or programs

	Type of unit	No. of patients	No. in social activities		No. in work/ education activities
Acute	High dependency	2	1	0	0
	Acute	15	11	6	0
Non-acute	Rehabilitation	20	17	8	2
	Extended care	58	42	30	23
Total		95	71	44	25

While most of the people in acute units (not HDU) had involvement in social activities, a low proportion (40%) accessed rehabilitation activities. Notably, we found that an equally low proportion of people in rehabilitation units had involvement in rehabilitation activities.

We noted that some people in rehabilitation or extended care units were able to access off-site activities. This included day programs, supported employment or TAFE, church services, and regular trips to town for personal shopping and/or lunch. One person with an intellectual disability attended an ADHC day program.

In the main, it was difficult to see a clear link between a person's involvement in an activity or program and any goals relating to their rehabilitation or preparation for discharge from hospital.

## 3.3.10 Patient and family views regarding discharge

Of the 80 people in our file review whose views were recorded, two-thirds (54) indicated that they wanted to be discharged. Of the 55 people whose family members' views were known, most (34) wanted the person to stay. While in some cases the view of family members and patients coincided, there were many instances where there was a difference of views.

Table 13: Patient and family views about discharge

		Family views				
		Wants person to leave	Wants person to stay	Mixed views	Unknown	Total
Person's	Wants to leave	11	15	5	23	54
views	Wants to stay	1	9	0	7	17
	Mixed views	2	5	0	2	9
	Unknown	2	5	0	8	15
Total		16	34	5	40	95

Among the 34 family members opposed to discharge, we noted they had expressed concerns that the person's condition would deteriorate in the community or that they felt the person was too unwell to be discharged. Sixteen family members were in favour of the person moving into the community immediately, or in the near future. We noted that some family members were actively looking for community accommodation options.

Seventeen patients were recorded as wanting to stay, one of whom has since been discharged. At least five of the 17 people were noted to be reluctant or anxious about their potential discharge from hospital.

Patients' views were unknown in 15 cases and families' views were unknown in 40 cases. It was not always clear why the views of individuals and their families had not been ascertained and/or recorded, although we note that some individuals did not have family involvement.

#### 3.4 Discharge planning

NSW Health's Discharge Planning for Adult Mental Health Inpatient Services policy sets out a structured discharge planning process that staff are required to follow to ensure the successful transition of people with mental illness from hospital to the community. It requires staff to involve the person, their family/ primary carer, and relevant health or community support providers in discharge planning; to undertake regular multidisciplinary reviews of the person; to assess the person's accommodation needs; and to develop a discharge care plan that includes medical and community support follow-up arrangements, and key referral services and programs.

We found that the level of discharge planning activity, and the quality of the work, varied widely across individuals, units, and mental health facilities.

Our consultant psychiatrists assessed that 13 patients in our review were not clinically well enough to be discharged. We therefore limited our analysis of discharge planning activity to 82 people.

Of these, we found that:

- There was no evidence that any discharge planning had occurred for one-third (26), all of whom were still admitted.
- There had been low-level<sup>54</sup> discharge planning activity for 18 people (22%). One person from this group has been discharged.
- Staff had undertaken medium-level<sup>55</sup> discharge planning activity for 31 people (38%). Ten of the 31 people have been discharged.
- There had been high-level<sup>56</sup> discharge planning efforts for seven people (9%). One person from this group has been discharged.

We found that the amount of discharge planning that occurred for individuals was highly variable, and there was no significant association with key factors such as the complexity of the person's support needs; the person's involvement in work and/or rehabilitation activities; or the views of family members.

<sup>54</sup> A low amount of discharge planning activity comprised some internal staff discussion and limited consultation with the patient and/or family members about discharge. There were few referrals to external agencies or support services.

<sup>55</sup> Medium activity involved a small number of referrals to agencies for accommodation and/or support services. Some patients had been placed on wait lists and some were on trial leave. There were often considerable periods of time between discharge planning actions.

<sup>56</sup> High activity typically comprised active work by staff to progress the person's potential exit from hospital. This included intensive and sustained efforts to identify and apply for community accommodation and/or support options; and coordination of discharge planning activities, such as multidisciplinary team meetings and reviews regarding discharge options and progress.

In our file review, there were two factors that were significantly associated with discharge planning activity. We found that people were significantly more likely to have a greater amount of discharge planning where:

- they had been granted unescorted leave;<sup>57</sup> and/or
- they had indicated that they wanted to leave.<sup>58</sup>

## 3.4.1 Discharge planning and patient views

Records indicated that five individuals in our file review had refused to consider or accept community accommodation placements that had been arranged, including two people who had declined more than one accommodation placement. The accommodation options included HASI, licensed boarding houses, residential aged care, and NGO supported accommodation.

Another four people had either refused to consider referral to specific accommodation options (HASI and a licensed boarding house), and/or had stated that they would only consider a specific regional location or accommodation option (home with mum).

The reasons for individuals' refusal of accommodation options were not always documented. One person declined a HASI offer as it meant extra travel to his supported employment, and a 66-year-old person declined a residential aged care placement on the basis that she wasn't ready. The two people who indicated they would only consider specific towns had immediate family in those locations.

In the main, we noted that, where a person had expressed a clear view regarding accommodation options and discharge planning, mental health staff took this into account.

## Case study 3

A 44-year-old man with schizophrenia, depression and a cognitive impairment had been in the mental health facility for over seven years at the time of our file review. He has a history of drug and alcohol abuse, extensive psychiatric admissions, and has spent time in prison. He has prominent psychotic symptoms, with hallucinations and other delusions. Mental health staff have noted that he is only partially responsive to treatment, and has no insight into his illness. He is not compliant with taking his medication, and demonstrates sexually inappropriate behaviour with female staff.

The man has stated that he wants to leave hospital and go back to the small country town he previously lived in. He was declined for a HASI package three years earlier, and has refused subsequent suggestions from his case manager to reapply. The man has stated that he only wants to live in the one country town. Mental health staff made inquiries about accommodation and support options in that town, and did not find any available facilities that could provide the support he requires. There was no indication of further discharge planning activity.

## 3.4.2 People with no discharge planning activity

Of the 26 people for whom no discharge planning had occurred, mental health staff had documented that nine individuals continued to require rehabilitation and/or considered that their mental state was not stable enough for them to be discharged.

A lack of appropriate community accommodation options with full-time care and supervision was reported to be the key reason discharge planning had not occurred for five people. These individuals had typically lived in hospital for over 10 years and had high support needs and/or difficult behaviour

<sup>57</sup>  $\chi$ 2[2] = 14.02, p = 0.0009

<sup>58</sup>  $\chi 2[1] = 9.46$ , p = 0.002

For 12 people, we could not find evidence to show why discharge planning had not commenced. In the main, these individuals were stable, did not demonstrate difficult behaviour, and did not have complex needs. This included three people over 65 years of age who appeared to be suitable for low or high level residential aged care, and three people for whom staff had recorded potential community accommodation options, such as HASI, but had not taken further action.

## 3.4.3 Accommodation and support options considered in discharge planning

Among the 56 people for whom there was evidence of discharge planning, the main accommodation options that had been considered or pursued included:

- ADHC-operated or funded disability supported accommodation (23)
- social housing with HASI support (12)
- LHD-operated or funded community residential services (11)
- residential aged care facilities (10)
- licensed boarding houses (9)
- transfer to another mental health facility (6)

Other options – such as living with family members and specialist homelessness services (or other accommodation services) – were also explored in a small number of cases.

#### We found that:

- for many people, only one or two options had been considered;
- there were extended periods of time with little or no discharge planning activity following a declined application, and no or delayed follow-up after a referral had been made; and
- some of the referrals made by mental health staff were not appropriate, in that the individual did not meet the eligibility criteria (such as for the CJP), or it was not age appropriate (such as referrals to aged care facilities for people younger than 65 years).

It was not always clear to us how mental health staff had identified the accommodation and support that the person would require in the community. While some had functional assessments and multidisciplinary reviews, this was not consistent practice.

## ADHC-operated or funded disability supported accommodation

Referrals to ADHC had been made in relation to 23 people, all but one of whom had an intellectual disability, a cognitive impairment, a neurological disorder, and/or a physical disability. Most of the people referred to ADHC (14) were recorded as having an intellectual disability.

Of the 23 people referred to ADHC:

- twelve people had been accepted onto the ADHC Register of Requests for Supported Accommodation;
- the applications for 10 people had been declined; and
- the outcome of one referral was not known at the time of our review.

#### Successful referrals

Of the 12 people accepted onto the ADHC supported accommodation register, the majority (9) had an intellectual disability that met ADHC's criteria; two people had an acquired brain injury (from hypoxic insult and neuroleptic malignant syndrome - see case study 4); and one person had a 'cognitive delay'.

Information relating to the length of time individuals had spent on the ADHC register was recorded for six people. This ranged from five months to 11 years, with three of these people waiting for more than two years.

Reasons recorded for the length of time on the register primarily related to a lack of vacancies in the requested area(s); and, for one person, a lack of accommodation options to meet their assessed need for 1:1 support. For a number of people on the register, mental health staff had recorded being advised by ADHC that it would be unlikely that the individual would ever be offered a place.

Five of the 12 people accepted onto ADHC's supported accommodation register have been discharged or offered an accommodation placement:

- Two people had been discharged by the time we reviewed their health files: one to an aged care facility; and one person with an intellectual disability and cerebral palsy was discharged into a HASI placement with HACC services, including case management, Meals on Wheels, and housekeeping.
- One person was separately referred to and accepted for a place in the ISP.

Two people have been discharged to ADHC group homes since our review.

#### Case study 4

A 44-year-old man living in a mental health extended care unit as a voluntary patient had been in hospital for over eight years at the time of our review. He has schizophrenia, an acquired brain injury as a result of neuroleptic malignant syndrome, relies on a walking frame for mobility, and has some speech difficulties.

The man's symptoms of mental illness are under control, although he still expresses delusions of his room being bugged and broadcast via television and radio. Mental health staff have noted that he tends to have outbursts and demonstrates some threatening behaviour if his needs are not met immediately or if he has trouble being understood.

He is largely independent with daily living activities, needing only minimal prompting. The man attends a work skills program off-site four days per week, and participates in a physiotherapy program to help his mobility.

He has been on ADHC's register of requests for supported accommodation for five years.

#### Unsuccessful referrals

For most of the 10 individuals whose applications to ADHC had been unsuccessful (6), the reason for non-acceptance was that they were considered to be ineligible for the requested services:

- three people were unsuccessful because of the ADHC policy exclusion of people with a primary diagnosis of mental illness – two of whom had an intellectual disability or 'severe' cognitive impairment;
- the referrals of two people were declined on the basis that they did not meet ADHC's criteria for intellectual disability (their IQ was considered to be over 70 and they were unable to demonstrate that the impairment occurred before the age of 18 years); and
- one person did not meet the criteria for eligibility to ADHC's CJP.

For four people, no reasons were recorded as to why their referral had been unsuccessful. There was no indication in the Health records that mental health staff had sought to appeal any of the decisions, or had considered escalating the matter with Health or ADHC management. ADHC information

indicates that mental health staff appealed one decision not to accept a person onto the supported accommodation register. The decision was upheld.

#### **HASI**

HASI had been considered for 12 people during their admission. Of the 12, eight had been approved, two had not yet been referred, and two had been declined because their needs were considered to be too high for the program. Of the eight people approved for HASI, two had been discharged to HASI placements. Two people had unsuccessful trial placements due to high support needs and deteriorating mental health.

### LHD-operated or funded community residential services

Referrals had been made for LHD-operated or funded community residential accommodation for 11 people. Of the nine people for whom the outcome of the referral was known, most (5) had been accepted, including two people who had been discharged.

The applications of four people were unsuccessful. Mental health staff recorded reasons for the decision in three cases, which included that the person's support needs were too high; they had a past history with the service; and they had 'personality issues'. There was no indication that mental health staff had sought to appeal any of the decisions, or had considered escalating the matter with Health or NGO management.

#### Residential aged care

Placement in residential aged care had been considered for 10 people. Three of the 10 people were discharged to aged care facilities.

Our file review identified a number of individuals whose placement in aged care facilities had been affected by the reported inability of these facilities to adequately manage their behaviours. This included individuals whose trial placements had failed; and individuals waiting for a place in a small number of aged care facilities that could reportedly meet their needs.

We also found mental health staff had made requests for Aged Care Assessment Team (ACAT) assessments, and referral and placement in aged care facilities, for people below the age of 65 years. This included one person who had been trialled in an aged care facility at the age of 57; and two people aged 60 who had been referred for aged care placement. We noted that one of the people currently considered too unwell for discharge had been the subject of several referrals to aged care facilities – most recently at the age of 53 years.

Three people referred for placement in residential aged care had expressed reluctance to go to the facility and/or had refused placement offers. One of the people who refused an offer was 60 years old at the time.

#### Licensed boarding houses

Placement in licensed boarding houses had been considered for nine people. Most (6) had subsequently been approved for entry to licensed boarding houses, including two people who were discharged. One person had been assessed as too vulnerable for placement in a boarding house, and two people had yet to be assessed for eligibility.

#### **Community support services**

We found that in-home or community support programs, such as HACC, Resources and Recovery, Personal Helpers and Mentors, and Support for Day-to-Day Living services were rarely considered as part of discharge planning. Two people were discharged with in-home support services – one with community aged care support, and one with HACC services.

## 3.4.4 Discharged patients

In total, 15 people in our file review were discharged during the course of our inquiry. Twelve people had been discharged by the time we reviewed their health files, to:

- social housing (4)
- aged care facilities (3)
- LHD-operated or funded community residential services (2)
- licensed boarding houses (2)
- a family member's home (1)

Three other people were discharged shortly after our reviews: one person to an ADHC group home; one to LHD-funded community residential accommodation; and one to social housing with HASI support.

One of the people discharged during the course of our inquiry subsequently died from natural causes.

Arrangements for clinical and social support after discharge varied from low level to intensive support. For three people, a number of different agencies were involved in providing high levels of support, such as HACC services, community aged care services, community mental health, and HASI services. Three people were discharged under Community Treatment Orders, including two of the people in social housing and one in an LHD-operated community residential service.

## Follow up information regarding discharged patients

In December 2011, we asked LHDs to provide information regarding the people who had been discharged during or soon after our visit, excluding the person who had died. We received the information between January and March 2012. At that time, all but one person were continuing to live in the community or in their residential aged care placements.

Two people had been readmitted to a mental health facility since being discharged:

- One man admitted himself voluntarily for one month before returning to his HASI placement.
- One woman was admitted for two days respite after living in social housing with high-level support from a number of organisations for almost three months. She was readmitted to the mental health facility one week later, and remained admitted as at February 2012.

Eight people were reported to receive case management by a community mental health or assertive outreach team. In one case, an NGO was undertaking medication management, rather than the community mental health team. The level of clinical support varied from daily contact for medication supervision for a few people, to monthly contact with a case manager and monthly visits to a Clozapine clinic for two people.

## 3.4.5 Additional patients identified by mental health staff

During the course of our file review, mental health staff in five facilities<sup>59</sup> told us about another 68 inpatients they considered could be discharged if appropriate community accommodation and support were available. In the main, the circumstances and support needs of these individuals were consistent with the 95 people in our file review. The key issues noted by mental health staff to affect discharge planning to safely and appropriately accommodate these individuals in the community were also highly consistent with the review group, and are reflected in the following sections of the report.

<sup>59</sup> Bloomfield, Concord, Lismore, Macquarie, and St George.

## Chapter 4 Key issues

We consulted with almost 300 people in the course of our inquiry, including Health; ADHC; other government agency staff; statutory bodies; non-government peak agencies; direct service organisations; consumers; carers; and advocates. These consultations, together with our review of the files of 95 inpatients, and our review of the legal, policy and service context, enabled us to identify a number of key issues.

## 4.1 Barriers to discharge within the health system

From our file review and consultations, it was evident that there are a number of factors within the health system that impede the effective discharge of mental health inpatients to the community.

A primary factor is the adequacy and effectiveness of the work by mental health facility staff to plan for, and facilitate, discharge to the community.

The depth of the following sections relating to barriers to discharge that exist within the health system is a reflection of the openness of mental health personnel and the cooperation and assistance of NSW Health and the Local Health Districts with this inquiry.

## 4.1.1 Discharge planning

Key elements of the discharge planning process set out in Health's policy require staff to:

- involve the person, their family/ primary carer, and relevant health or community support providers in discharge planning;
- undertake regular multidisciplinary reviews of the person;
- assess the person's accommodation needs; and
- develop a discharge care plan that includes medical and community support follow-up arrangements, and key referral services and programs.

The policy also requires (then) Area Health Services to develop local protocols relating to discharge planning, including:

- details as to personnel roles and responsibilities;
- · staff education and training; and
- information regarding referral networks, comprising community health care providers, other government providers and NGO contacts.

However, our file review and consultations indicated that mental health staff are not consistently applying the policy.

## Assessments and discharge planning

We found that the link between assessments or reviews of the person and discharge planning activities was not always evident. Notably, we identified that:

• the preparation of reports and other information for MHRT review hearings did not consistently prompt mental health staff to review discharge planning activities and progress, or to undertake an assessment to determine the person's readiness for discharge; and

where staff had expressed an opinion that an individual needed 24/7 supported
accommodation, it was not always clear how that decision or assessment had been reached.
For example, opinions of this kind were not consistently supported by evidence of a formal
assessment of the person's functioning and/or risks.

In relation to assessments of risk, mental health staff told us that there is a tendency for discharge planning decisions to be highly risk averse, and where there is any doubt, a conservative approach is taken.

## Adequacy of efforts to progress discharge planning

Our file review indicated that, across different facilities and units, the amount of discharge planning activity was highly variable. In fact, the nature of discharge planning was often influenced by factors other than the person's clinical wellness and availability of community accommodation and support.

Our consultations with mental health staff in relation to the 26 people who were clinically well enough to be discharged but for whom there had not been any discharge planning reinforced the evidence from our file reviews. Reasons provided by mental health staff for the lack of discharge planning activity included that they thought the individuals were too unwell; that past attempts at community living had been unsuccessful and this was likely to happen again if discharged; that individuals were reluctant to be discharged; and/or that their families were opposed to discharge. Staff also told us that their discharge planning efforts were influenced by the lack of suitable supported accommodation options in their area, particularly those providing 24/7 support.

In relation to the individuals for whom there had been discharge planning, we often identified long periods of time between referrals being made and mental health staff following up options; and extended delays between staff documenting an intended action – such as making a referral to a particular service – and carrying it out. Overall, the amount and quality of the discharge planning activity undertaken in relation to the people in our file review suggested that this work was not consistently viewed as a priority by mental health staff.

## Referrals to, and work with, community accommodation and support providers

We found mixed practice in relation to the options explored by mental health staff and in their work with community accommodation and support providers to facilitate discharge. Staff in some mental health facilities appeared to link in with a range of providers to arrange support for the individual; this included HACC services, aged care packages, and community mental health support. Staff in other facilities tended to consider the same limited options for many individuals. In some cases, these limited options may have reflected the available services in the area; however, this was not always the case.

- In some districts, we found that there did not appear to be a comprehensive understanding of the available accommodation and support options. Referrals focused primarily on the same licensed boarding houses.
- In many cases, mental health staff had insufficient knowledge about the eligibility criteria
  of agencies and programs. This meant that staff were investing time and energy in making
  inappropriate referrals such as to the Integrated Services Program before exploring other
  options; and inappropriate referrals to the Community Justice Program for people without an
  intellectual disability and who were not in custody.

We note that, under the current discharge planning policy, each (then) Area Health Service was to develop a local protocol that included details of referral networks. The limited range of options considered in some districts, and the limited knowledge of mental health staff regarding community

services and programs, raises questions about the adequacy of the referral networks content in the local protocols that have been developed.

However, as discussed in the following sections of this report, we appreciate that mental health staff are undertaking discharge planning in the context of numerous challenges. These include an insufficient supply of long-term and highly supported housing options; and the exclusion of people with a primary diagnosis of mental illness from the majority of the accommodation options provided by the disability sector.

#### 4.1.2 Mental health staff factors

The knowledge of mental health staff about available and appropriate accommodation and support options and associated eligibility criteria and application processes, is critical to discharge planning. Our file review and consultations identified that the availability of mental health staff and their attitudes also affect discharge planning.

We heard that discharge planning has been adversely affected by gaps in staffing in some mental health facilities; particularly in relation to positions such as social workers and occupational therapists, who are important in undertaking the assessments and planning for discharge. Reported reasons for the staffing gaps varied across the facilities, and included funding limitations, recruitment freezes, and difficulties attracting staff to regional areas.

It was evident from our file reviews and consultations that mental health facility staff care about the individuals they support, and seek to ensure their safety and wellbeing. However, staff attitudes about the welfare and capability of individuals can also have a direct impact on discharge planning. This includes:

- the belief that some patients are better supported in hospital than in the community;
- protective concerns relating to past community placement attempts that have failed; and
- a focus on deficits and previous risks.

## 4.1.3 Mental health facility factors

## Elements that work against discharge

In our file review, it was difficult to see a clear link between an individual's involvement in rehabilitation activities, or placement in a rehabilitation unit, and discharge planning efforts.

Many people we consulted – including consumers, carers, NGOs, and mental health staff – told us that the hospital setting affects the ability of patients to undertake effective rehabilitation and preparation for discharge. We heard that:

- patients have limited opportunities to learn or regain living skills due to hospital provision of meals, laundry and cleaning services;
- the hospital setting affects the ability of staff to assess the functional capacity of individuals, particularly where the training facilities are limited or out-dated; and
- the rehabilitation and work programs are not consistently linked to meaningful goals for individuals or assessments of achievements.

We found that the location of some of the mental health facilities adversely affects rehabilitation activities and preparation for discharge. Our file reviews and consultations showed that the location of some of the facilities away from towns or accessible transport means that patients rely on staff for access to the community, including for shopping and attendance at work.

In relation to rehabilitation and preparation for discharge, consumers and others also raised concerns with us that clinical interventions tend to be narrowly focused on medication management; and that access to psychosocial counselling or other therapeutic approaches is limited.

## Rehabilitation units are now long-stay units

Our work indicates that rehabilitation units in mental health facilities are not consistently being used for this purpose. We found that rehabilitation beds, designed to be transitional accommodation, have, in many cases, become long-stay or permanent accommodation for individuals.

We were told that the use of rehabilitation units to accommodate extended stay patients creates bed blockages that have systemic repercussions – including reducing the capacity of facilities to admit and retain people who are clinically unwell, and to step-down patients from acute units to less intensive rehabilitation units.

In more than one facility, we heard from staff that pressure for acute beds for new admissions has led to internal shifting of patients around units and/or the use of patient leave from hospital to make space for new patients, reportedly to the detriment of patients' care and well-being.

Mental health staff told us that many of the extended stay patients accommodated in hospital rehabilitation units are unlikely to benefit from the clinical rehabilitation focus. The expert clinicians we consulted assessed that the majority of the people in our file review required ongoing and intensive disability support rather than short-term clinical rehabilitation.

## 4.1.4 The needs and wishes of patients

Our file review and consultations identified that a particular challenge in progressing the discharge of people who have lived in mental health facilities for years related to overcoming the effects of institutionalisation. Some people in our file review viewed the mental health facility as their home; were heavily dependent on staff for support with most daily activities; and were highly reliant on set routines.

We note that disability services provide support to many people with disabilities who have moved out of institutional settings into community accommodation. These services have successfully implemented strategies to assist individuals to ameliorate the effects of institutionalisation.

While there were complexities in the presentation and support needs of many of the people in our file review, the view of the expert clinicians was that most could live successfully in the community with appropriate accommodation and support. In fact, there were only three people who the expert clinicians advised would be likely to need a secure environment and/or intensive clinical support.

## Discharge planning and the wishes of patients

NSW mental health legislation and discharge planning policy make it clear that consumers are to be involved in the development of plans for their treatment and ongoing care, including the discharge care plan.

We noted the involvement of people in our file review in discharge planning, including evidence that the views of individuals were taken into account by mental health staff and other services. For at least nine people in our file review, their views presented barriers to their discharge from hospital. This cohort included individuals who stated that:

- they did not want to leave the hospital despite being clinically well enough to do so;
- they were only prepared to live in one location in a regional area; or
- they would not accept the proposed accommodation and support options, such as a HASI package

#### Case study 5

A 49-year-old man with schizophrenia and a mild intellectual disability had been in hospital for over three years at the time of our review. He needs prompting with daily living activities, but does not have current challenging behaviour or complex support needs. He travels independently to supported employment, and lives in a long-stay rehabilitation unit. Mental health staff have encouraged the man to move to a lower-support cottage, but he has stated that he does not want to leave his current unit, and he wants to stay in the hospital.

A year before our review, the man had been offered a high-support HASI place in a suburb about 30 minutes from the mental health facility, and 15-20 minutes from his supported employment location. Mental health staff recorded that they declined the HASI placement as it was felt that the man would be disadvantaged by the move, as he would not be as close to his family or supported employment. Six months later, the man was again assessed for HASI, but stated that he did not like the plan of moving to a HASI placement. There was no indication of further discharge planning activity.

It is appropriate that the views of the patient are heard, and that they directly influence discharge planning. However, some of the examples in our file reviews raised questions about:

- the extent of the work undertaken by staff of mental health facilities, and other agencies involved in discharge planning, to assist the person to address their concerns and to consider alternative options; and
- the extent to which mental health facilities should continue to accommodate individuals who
  are clinically well enough to be discharged, and have declined reasonable and appropriate
  community options.

We also found that the reasons for a person declining the accommodation and support option were not always clear; and there did not appear to be a trigger for mental health staff to look at what other action may be required – such as a case conference, discussion with senior personnel, and/or development of strategies – to address the person's concerns.

From our file review, it was not clear whether, and how, some patients' objections or refusal of reasonable options were taken into account in mental health staff's assessment of their readiness for discharge. The continued accommodation in mental health facilities of individuals who have been offered appropriate and less restrictive care does not appear to be consistent with the principles of the *Mental Health Act 2007*.

#### 4.1.5 Inter-Local Health District transfers

Our file review showed that, at times, patients need a program or level of care that is not available in their current mental health facility. For example, a patient in a hospital with only acute care beds may need access to a rehabilitation unit. As a result, transfers between facilities, and between LHDs, may be necessary.

However, our consultations with mental health staff identified that it is very difficult to transfer patients between hospitals in different LHDs. As a result, patients can remain in inappropriate hospital placements. According to health staff, key reasons for the difficulties in transferring patients relate to the transfer of cost for out-of-area patients, and the heavy demand for admission to all mental health facilities from within districts.

We were advised that it is particularly difficult for districts that have never had a stand-alone psychiatric hospital, and do not have a variety of unit options. Stand-alone hospitals that used to accept larger numbers of out-of-area placements have reportedly become increasingly difficult to access.

Where a placement is sought in a different facility but is declined, matters can be escalated to higher levels for discussion between Mental Health Directors or by a Complex Care Committee at the central office level. However, mental health facility staff expressed concerns about the effectiveness of the Complex Care Committee, reporting that it has no power to enforce acceptance of a patient. LHDs operate as separate entities, and make their own decisions about acceptance of patients and allocation of mental health beds; the beds are not, typically, state-wide resources.

We heard that successful transfers often depend on personal relationships and goodwill between mental health staff rather than consideration of which patients are most in need of which beds and programs. There does not currently appear to be a coherent system for the allocation and transfer of patients in mental health facilities to ensure that individuals receive the most appropriate service to meet their needs.

## 4.1.6 Legal processes

## **Decisions about less restrictive care options**

Our file review has raised questions about the adequacy of the information provided by mental health staff to the MHRT to inform its decisions about whether patients need to remain in hospital. Our file reviews indicated that the MHRT is being provided with inaccurate and/or inadequate information regarding the availability of less restrictive care. In a number of cases, staff or individuals had refused to accept offers of less restrictive options; and in others there had been no or minimal discharge planning undertaken to establish whether appropriate options were available.

In addition, preparation for MHRT review hearings did not consistently involve staff undertaking a current assessment or multidisciplinary review of the individual to inform their report, or reviewing the progress of discharge planning.

We noted that, at times, the MHRT had set an earlier review date for individuals, and/or sought additional and specific information from mental health staff for the next review. MHRT members confirmed that a range of factors influenced their decision-making. The Tribunal is an inquisitorial body and has no capacity to investigate, but members can seek more information, such as assessment reports, or they can set an early review date, or ask for a particular person to appear, if evidence at a hearing indicates that is necessary.

## Representation

Our file review identified a low level of patient access to legal representation at MHRT reviews. We understand that legal aid is not routinely offered or provided for reviews of involuntary patients who have been in hospital for more than 12 months, and is not provided for voluntary patients.

Following our discussions with the Mental Health Advocacy Service (MHAS) – the division within Legal Aid that undertakes most of the legal representation at MHRT hearings – the MHAS decided to review its approach to advising non-acute patients in mental health facilities. The MHAS has since written to social workers in non-acute units in order to seek their assistance in providing information for involuntary patients about their appeal rights and about how to apply for legal aid. <sup>60</sup>

<sup>60</sup> Verbal advice from MHAS staff, August 2012.

## 4.2 Barriers to discharge in the community service system

It is evident that there are people living in mental health facilities who could be discharged from hospital if adequate and appropriate community supports were available. The NSW Government has estimated that 'around a third' of people with longer term admissions (more than 500 days) could be discharged if appropriate accommodation and supports were available in the community. <sup>61</sup> This was supported by mental health staff in our consultations, who reported that between 30 and 60 per cent of the people in their facilities could be discharged if the community supports were in place.

We found that appropriate community supports, including clinical support and highly supported and long-term accommodation, are in short supply and this is preventing the discharge of people from hospital. In addition, there are community supports, including most accommodation provided by the disability sector, that are typically unable to be accessed by people living in mental health facilities because of their diagnosis and/or location.

## 4.2.1 Availability of clinical mental health support in the community

People with chronic and severe mental illness need clinical support in the community in order to maintain optimal mental health and promote recovery.

NSW Health's *Community Mental Health Strategy 2007-2012* included increased investment across community mental health services. This incorporated greater investment in areas such as community mental health emergency care; specialist mental health services; and adult community mental health services (including Assertive Community Treatment services for people who have numerous and frequent acute inpatient admissions).

However, many people we consulted with, both inside and outside of NSW Health, raised concerns with us about the availability and adequacy of community mental health support. Reported concerns included that community mental health teams do not currently have the capacity to provide sufficient and timely support. We heard that the capacity of the teams is adversely affected by:

- excessive caseloads;
- persistent gaps in community mental health team staffing in some districts due to staff turnover, reported delays in undertaking recruitment, and difficulties in attracting staff;
- a shift in locus of care from the community to Psychiatric Emergency Care Centres in hospital emergency departments; and
- an occupational health and safety focus that often requires two staff to conduct home visits.

We were told that many community mental health teams are stretched to such an extent that support is often limited to medication administration and/or monitoring, and there is insufficient capacity for staff to form a relationship with the person to enable effective case management. Consumers and families told us about the recent difficulties they have experienced in trying to obtain a timely and sufficient response from community mental health services.

Mental health facility staff told us that the limited capacity of community mental health teams has a direct impact on the discharge planning process – it adversely affects the acceptance of referrals, and influences staff decisions about whether a patient could be appropriately discharged to the community.

Importantly, a number of senior mental health staff, including mental health directors, told us that they are more concerned about people with mental illness currently living in the community than they are about inpatients who remain in mental health facilities despite being clinically well enough

<sup>61</sup> NSW Government (2010) Draft NSW Government submission to the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme, p.106.

to be discharged. While acknowledging the latter to be a problem that needs to be addressed, they indicated that they have serious concerns about the larger number of people with significant mental health problems living by themselves in the community who are at risk due to the paucity of available and adequate clinical support.

Not unreasonably, the vast majority of the people in our file reviews did not have the current involvement of community mental health teams. However, we noted good practice on the part of community mental health in relation to some individuals. This included acceptance of referrals for support of individuals as part of the discharge plan; and, for one woman, continued involvement during her admission to hospital and active work to sustain her community support arrangements.

## 4.2.2 Access to accommodation and support under the Disability Services Act 1993

It is clear from our inquiry that, while people with a psychiatric disability are included in the target group for services under the DSA, they do not have consistent access to the full range of disability services. In particular, people with a primary diagnosis of mental illness and associated disability do not have access to the majority of supported accommodation that is funded under the Act.

Part of the reason for this is the blanket exclusion of people with a primary diagnosis of mental illness from supported accommodation that is available under ADHC's *Allocation* policy, on the basis that Health is considered to have responsibility for providing this support. However, we found that it is not just this exclusion that appears to be limiting the access of people with psychiatric disability to services under the DSA.

## Eligibility for services under the DSA

All but two of the 95 people in our file reviews were in the target group of the DSA, because they had a permanent disability that:

- was attributable to a psychiatric impairment and, in many cases, to a combination of impairments particularly psychiatric and intellectual impairments;
- had resulted in a significantly reduced capacity in major life activities, including self-care, decision-making, learning, communication, and/or mobility; and
- had resulted in the need for support. (For many of the 93 people, their need for support was likely to be ongoing).

Many of the individuals in our file review had high support needs related to their functional impairments. We found that their day-to-day disability support needs were not dissimilar to many people living in supported accommodation that is funded under the DSA. (That is, they needed assistance with activities of daily living, particularly self-care activities and decision-making; supervision and a structured living environment; assistance to meet their needs relating to physical health, employment, and community integration; and support to increase their independence).

Table 14 illustrates the similarities between the accommodation and support needs of three individuals with a psychiatric disability who reside (or resided) in three different forms of accommodation: one in an ADHC group home; one in an NGO group home following the closure of a licensed BH; and one in a mental health facility.<sup>62</sup>

We reviewed the circumstances of the first two individuals in the course of our role in reviewing the deaths of people with disabilities in care. The third person was one of the 95 mental health inpatients in our file review.

Table 14: Comparison of people with psychiatric disability in varied accommodation

Disability accommodation	Boarding House Relocation Program	Mental health facility
<ul> <li>64-year-old man lived in an ADHC group home.</li> <li>Had chronic schizophrenia and a mild intellectual disability that was noted to be linked to his mental illness.</li> <li>Required supervision and assistance with daily living activities, including meals and medication.</li> <li>Saw a neuropsychiatrist regularly, and had mental health facility admissions related to psychotic episodes. Last admission was for seven days.</li> <li>Behaviour support plan guided staff in signs of potential relapse in his mental illness, and when to contact the crisis mental health team, GP, and psychiatrist.</li> <li>Attended day programs operated by a disability NGO and a mental health NGO.</li> </ul>	<ul> <li>54-year-old woman lived in an NGO group home after the closure of a licensed boarding house – via the Boarding House Relocation Program.</li> <li>Had chronic treatment-resistant schizophrenia.</li> <li>Required supervision and assistance with daily living activities, including self-care and medication.</li> <li>Had ongoing symptoms of mental illness, including anxiety and auditory hallucinations about people trying to kill her.</li> <li>Displayed obsessive behaviour relating to cigarettes, and some aggression.</li> <li>Had fortnightly reviews with the community mental health team, and attended a Clozapine clinic.</li> </ul>	<ul> <li>39-year-old woman has been in hospital for three years, and is currently living in a secure rehabilitation unit as   a voluntary patient.</li> <li>Has schizophrenia and an intellectual disability, with an IQ that has been variably assessed as 66 and over 70.</li> <li>Has difficulty learning new skills, and requires high-level supervision, support and assistance with daily living activities.</li> <li>Has a stable mental state with no current evidence of disturbed behaviours.</li> <li>Tends to throw away or hide clothing; can be intrusive and demanding towards staff.</li> <li>Was referred to ADHC for accommodation, but was declined on the basis of primary diagnosis of mental illness.</li> </ul>

While the 93 people were in the target group of the DSA, we found that very few had access to services under that legislation, or had been identified as potentially eligible for those services.

#### Overall, we found that:

- eligibility of individuals appeared to depend heavily on the person's diagnosis rather than their functional impairments or disability, and it was not always clear how primary diagnosis had been established;
- application of the *Allocation* policy appears to be inconsistent;
- potential eligibility of people with an acquired brain injury (or other cognitive impairment) for ADHC-funded accommodation and/or support, rarely appeared to be considered by ADHC or Health;
- people with a primary diagnosis of mental illness may be eligible for some supported accommodation provided by disability services under the DSA, but the places are very limited (such as the ISP); or people living in mental health facilities either do not, or are unlikely to, meet the eligibility criteria of specific programs (for example, YPIRAC, CJP, and BHRP); and
- people with a primary diagnosis of mental illness may be eligible for other community support services not funded under the DSA, such as HACC services, but it does not appear that these services are regularly considered by mental health staff as part of discharge planning.

#### Focus on eligibility for ADHC-operated services

In our file review, we found that mental health staff referred very few people to ADHC for supported accommodation under the DSA. Of the 80 people in our file review who were well enough to be discharged and who were in the target group of the DSA, referrals had been made to ADHC for just over one-quarter (23). Just over half of these individuals (12) had been accepted onto the register for supported accommodation; most of whom met ADHC's criteria for intellectual disability.

For those referred to ADHC for supported accommodation, the focus frequently appeared to be on ascertaining the person's eligibility for ADHC-operated services (that is, the age at onset and level of intellectual disability), rather than eligibility for broader disability services. There did not appear to be consistent consideration by ADHC of potential eligibility for accommodation and support provided by ADHC-funded NGO services.

Mental health staff also appeared to focus on eligibility for ADHC-operated services, rather than funded disability services. We found that mental health staff only tended to make a referral to ADHC for individuals they considered to have an intellectual disability or an otherwise significant level of cognitive impairment. The 22 people with cognitive impairment referred by mental health staff to ADHC represented less than half of the 51 people in our file review who had a cognitive impairment and were clinically well enough to be discharged.

Mental health staff told us that they stopped referring people to ADHC because of the policy exclusion. However, it was also clear in our consultations with mental health staff that few were aware of the different eligibility criteria between ADHC-operated services and the NGOs funded by ADHC.

A focus by ADHC and mental health staff on eligibility for ADHC-operated services limits the potential access of people with ABI and other cognitive impairments to services under the DSA, and presents other challenges for inpatients, families and mental health staff. The ability of inpatients and mental health staff to prove that the person had an intellectual disability before the age of 18 years is difficult, particularly where the person does not have family involvement or has limited early records.

#### **Primary diagnosis**

The dominant factor determining whether a person in a mental health facility has access to supported accommodation operated or funded by ADHC is whether they have a primary diagnosis of mental illness. As it stands, the *Allocation* policy indicates that an individual can be excluded from supported accommodation under this policy if they have a primary diagnosis of mental illness. The effect of this policy – which appears to be ultra vires – is that people with a primary diagnosis of mental illness are being excluded from their rights under the DSA, even in circumstances in which a support needs assessment would indicate the appropriateness of supported accommodation.

As noted in section 2.2, not everyone with a diagnosed mental illness has a disability or requires disability support. The focus of this inquiry is people with mental illness who have a disability as defined by the DSA: that is, people who have a permanent (or likely to be permanent) disability that is attributable to a psychiatric (or other) impairment, or combination of impairments, and that results in a significantly reduced capacity in one or more major life activities; and who have the need for support.

Our inquiry has found that reliance on primary diagnosis of mental illness to determine eligibility for disability services – or exclusion – is highly problematic. In large part, this is because this approach does not adequately take into account the individual's functional impairments and psychiatric disability – the key reason why they need the disability service or supports.

It is clear from our file reviews that it was the functional impairment(s) and associated disability of the individuals that indicated the level and type of support they required, not their primary or other diagnosis. All of the people in our file review had a diagnosed mental illness and ongoing clinical mental health support needs, but they also had significant functional impairments in their decision-making, self-care, and other daily living activities, for which they required intensive and ongoing disability support.

Importantly, we found that the functional impairments and disability support needs of individuals were largely consistent, irrespective of whether the disability arose from their mental illness, or from a coexisting intellectual disability or ABI.

Separately, our inquiry found that it is not clear how ADHC determines whether mental illness is a person's primary diagnosis, and there is no guidance on this critical issue in the *Allocation* policy or other ADHC policies. Our inquiry also raised questions about whether the *Allocation* policy requirements are applied consistently.

#### For example:

- It was not clear how the primary diagnosis of the 12 people in our file review accepted onto ADHC's supported accommodation register had been determined. While they all had an intellectual disability, an ABI, or an unspecified cognitive delay, they also had a diagnosed mental illness, and had similar histories and presentations to other people in the file review who were considered to have a primary diagnosis of mental illness.
- There are 73 people on ADHC's supported accommodation register whose primary disability (the one requiring most support) is psychiatric. In response to our request for advice as to what criteria the individuals had met to be placed on the register, ADHC pointed to the eligibility criteria and exclusions outlined in the *Allocation* policy. While this suggests that they were not considered to have a primary diagnosis of mental illness, it is not clear how this would have been established by ADHC.

The above information illustrates the problems associated with determining eligibility based on primary diagnosis alone, and excluding individuals on this basis. By itself, a diagnostic approach is not an equitable means of determining access to services; it does not provide a comprehensive measure of support needs; and it can be inconsistently applied due to differing interpretations.

The Productivity Commission has recommended that the assessment criteria to determine eligibility for the NDIS should use the mix of indicators that best measure support needs; that is, combine functional criteria with examples of relevant condition-based criteria. This is consistent with the criteria used to ascertain eligibility for services under the DSA.

We note that *Stronger Together* includes a commitment to make access to disability services and allocation of resources fairer, more transparent, and based on a standardised assessment of a person's functional need. This would assist people with a psychiatric disability, provided that ADHC also removed the existing diagnosis-based exclusions.

ADHC has advised that '[u]se of the term 'primary disability' ought not to preclude a person from accessing any particular support', and that where service needs are shared across agencies, those agencies should work collaboratively and negotiate resource allocation to ensure the person's needs are met and the most appropriate support is provided.<sup>63</sup>

This is consistent with the ADHC/ Health MOU relating to support for people with dual diagnoses of intellectual disability and mental illness. However, the problem is that in practice, a person with a primary diagnosis of mental illness and a psychiatric disability can be precluded from accessing particular support funded under the DSA.

## Responsibility for providing accommodation and disability support to people with psychiatric disability

On a related note, it is apposite to consider the position taken by the Productivity Commission in its Disability Care and Support inquiry. In its draft report, the Commission canvassed views on whether people with mental illness should be included in the scope of the proposed NDIS. In its submission, the (then) NSW Government stated that 'at a minimum, the roles and responsibilities should be consistent with the *Disability Services Act 1993*; that is, disability services assist with activities of daily living, with mental health services responsible for clinical management and rehabilitation'.<sup>64</sup>

<sup>63</sup> ADHC advice, 5 April 2012.

<sup>64</sup> NSW Government (May 2011) NSW Government Response to the Draft Report on Disability Care and Support, p.45.

The Government's response indicated that the NDIS could fund NGO disability services to provide supported accommodation and other services to people with psychiatric disability, but the mental health sector should retain responsibility for accommodation that involves integrated specialist support with clinical support functions (such as HASI).

The Government's view included that there would need to be:

- a 'collaborative person-centred approach to planning' to determine the sector(s) that best meets the identified needs of individuals;<sup>65</sup>
- a joint strategy to build cross-sector capacity and skill sets, and a joint understanding of roles and responsibilities; and
- brokerage capacity in both the mental health and disability support sectors to purchase appropriate supports from the other sector as needed.

There are some notable differences between the (then) Government's views as to where responsibilities for providing support to people with psychiatric disability should lie under the proposed NDIS, and the current ADHC and NSW Health arrangements. The position put forward by the Government includes a clear role for the disability sector in providing supported accommodation and other services to people with psychiatric disability, and a need for consistency with the DSA.

In addition, while the ADHC/ Health MOU includes elements of the joint strategy and collaborative and person-centred approach to planning put forward in the Government's response, as previously noted this only relates to people with a dual diagnosis.

In its final report, the Productivity Commission, consistent with the view advanced by the NSW Government, contended that the NDIS should meet the disability support needs of people with significant and enduring psychiatric disability who have scope to be supported in the general community. The Commission noted that this reflected the similarities in support needs and the broad principles underpinning the mental health system and disability supports generally.

The final report recommended that clinical care should rest with the mental health sector, and the disability sector (NDIS) should have a role in meeting community-based, disability support needs, including accommodation-based supports for people who do not require on-site clinical services. Our inquiry supports the Commission's views.<sup>66</sup>

#### **Prioritisation**

Placement on ADHC's supported accommodation register does not guarantee an accommodation placement. Allocation decisions are based on the individual's assessed need relative to other applicants, and consideration of a range of factors, including the profiles of the other people living in the supported accommodation unit.

Prioritisation is given to people who are homeless or effectively homeless, or at imminent risk of homelessness. The ADHC/Health MOU indicates that homelessness includes people who are inappropriately occupying a mental health bed.

Of the 12 people in our file review who were accepted onto the supported accommodation register, two people subsequently moved into ADHC group homes. The individuals had been on the register for over two years.

<sup>65</sup> Ibid., p.46.

We heard from some staff in ADHC that ADHC-operated and funded disability services are not equipped to provide support to people with a primary diagnosis of mental illness and psychiatric disability, indicating that this support requires specialist skills. We note that ADHC-operated and funded services currently provide support to people with primary and secondary psychiatric disability. In addition, the minimum qualifications and skill requirements for staff providing disability support are largely consistent across the disability and mental health sectors. It is only staff in LHD-operated services that have clinical mental health expertise.

Mental health staff told us that mental health facility inpatients are not considered to be a priority because they have accommodation and support. The lack of evident progress towards gaining a disability supported accommodation placement for people accepted as eligible for such placement was reported to be a great source of frustration for mental health social workers and others involved in discharge planning.

We note that, while individuals in our file review had been on the supported accommodation register for a considerable period of time, this is also the case for many people living in the community. Demand for supported accommodation for people with disabilities exceeds its supply; hence the need for an equitable allocation process based on prioritisation of need.

We were told by mental health staff, and read on files, that ADHC had indicated that placement for some individuals would be unlikely – because the person had agreed to placement only in a specific town; the person required 1:1 support that was not available in that region; or others had greater need.

It is reasonable to expect that these factors would adversely affect the length of time those individuals may wait for disability accommodation. In addition, we note that other factors are likely to have affected the length of time the people in our file review had been on the register. For example, some people had been placed on the register for 'future needs' rather than 'immediate needs', suggesting that the message regarding a high need for placement had not been adequately communicated and/ or received.

## 4.2.3 Availability of appropriate community-based accommodation and support

# Previously reported gaps in community-based accommodation and support

Numerous inquiries and reports have drawn attention to critical gaps in the availability of appropriate supported accommodation for people with mental illness, and called for reform.

The Richmond Report in 1983 recommended the funding of NGOs to provide hostel and group home accommodation for people with mental illness, and indicated that a network of services – including hospital care, health teams, supported accommodation, rehabilitation services, and crisis care – was fundamental.<sup>67</sup>

Since 1983, multiple inquiries into mental health and/or acute services have repeatedly reported two key problems:<sup>68</sup>

- 1. People are remaining in mental health facilities due to inadequate discharge planning and a lack of suitable supported accommodation options available in the community; and
- 2. There is a continuing unmet need for long-term step-up and step-down sub-acute community accommodation, and 24-hour supported accommodation.

Most recently, the 2008 Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals (the Garling Report) reported that inpatient units were 'unnecessarily full because there were

<sup>67</sup> Richmond, D T (Chair) (1983) *Inquiry into Health Services for the Psychiatrically III and Developmentally Disabled,* (the Richmond Report).

<sup>68</sup> Inquiries include the 1993 HREOC Inquiry into Human Rights of People with a Mental Illness (the Burdekin Report); the 2002 NSW Parliament Legislative Council Select Committee on Mental Health Inquiry into mental health services in NSW; the 2008 Australian Parliament Senate Standing Committee on Community Affairs Inquiry into mental health services in Australia; and the 2008 Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals.

inefficiencies in discharging patients', including discharge barriers caused by insufficient community mental health services and sub-acute accommodation options.<sup>69</sup>

The report indicated that, while HASI was alleviating the accommodation problem to an extent, there remained 'a large gap between what HASI provides, and the need for the services.' The report noted the pressing need for more sub-acute accommodation in the community, as recommended by the Richmond Report, and commented that this supported housing appeared to be the 'missing link' in the mental health systems and services that are available.<sup>70</sup>

The NSW Government has previously identified gaps at both the higher and lower ends of the support continuum, as measured against NSW Health's *Framework for Housing and Accommodation Support*. The framework identifies six levels of accommodation and support required to meet the spectrum of support needs of people with mental illness:

- **A. Inpatient non-acute services** for people with high to very high disability, and who present a safety risk to themselves or others.
- **B. Very high support** 24/7 extended non-acute care of a medium to long-term duration to provide stabilisation of symptoms and behaviour, and disability support.
- **C. Residential rehabilitation** 24/7 non-acute care of a short to medium-term duration, with a focus on intensive rehabilitation and facilitating community participation.
- **D. High support** support provided 8-16 hours per day, 5-7 days per week, with 24 hour oncall availability, over a medium to long-term duration, to provide stabilisation of symptoms, maintenance of functioning, and facilitate community participation.
- **E. Medium support** support provided over a short, medium or long-term duration, with 2-5 visits per week, to provide early intervention, stabilisation of symptoms, maintenance of functioning, and facilitate community participation.
- **F. Low support** support provided to people with low to no disability, over a short, medium or long-term duration, with 1 visit per week and 1-2 visits per month to provide early intervention, prevention, and maintenance.

In August 2010, the (then) NSW Government's submission to the Productivity Commission's Disability Care and Support Inquiry indicated that HASI had evolved to provide a range of support across levels C to E.

The Government's submission indicated that:

- With intensive rehabilitation over a considerable period, 'about 40%' of the current group of patients receiving Level A support in mental health facilities 'may be transferable to a slightly lower level of support, but this remains to be established.<sup>71</sup>
- Level B support, providing 24/7 support over the medium to long-term, corresponds to X-HASI (extended HASI), which was (then) the subject of consultation.
- The gap in the NSW range of disability support services is a level below Low HASI, corresponding to levels E and F in the framework.

<sup>69</sup> Garling, P (2008) Final report of the Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals, pp.803-804.

<sup>70</sup> *Ibid.*, p.804, and pp.814-816.

<sup>71</sup> NSW Government (August 2010) *Draft NSW Government submission to the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme*, p.105.

## Issues identified in our inquiry regarding access to community-based accommodation and support

Our inquiry indicates that the key problems reported in the previous inquiries and submissions continue to be critical factors in why people remain in mental health facilities beyond the point at which they clinically need to be there. In particular, we found that there is a strong need for a wider range of community accommodation and support options for people with severe mental illness and enduring psychiatric disability, including long-term and 24/7 supported housing options.

### There are not enough long-term and highly supported housing places

Our file review and consultations have clearly identified critical gaps in the availability of communitybased accommodation options that provide very high support on a long-term or ongoing basis (Levels B – D in the framework). We found that a lack of appropriate options is a key factor:

- preventing the discharge of mental health inpatients to the community;
- blocking rehabilitation beds in hospital and the community; and
- influencing mental health staff to refer inpatients to inappropriate options such as to residential aged care for people younger than 65 years - in an attempt to locate alternative sources of long-term and highly supported accommodation.

Our expert clinicians identified that the majority of the people in our file review required long-term supported accommodation in a structured living environment, with on-site disability support and supervision for 16-24 hours per day, and access to timely and responsive community mental health support. This type of accommodation and support – whether provided by the disability or mental health sectors – was most commonly sought by mental health staff in undertaking discharge planning.

However, our file review demonstrated the existing problem of insufficient supply of this accommodation to meet the evident demand – only eight of the 34 people referred to ADHC or Health for highly supported accommodation in the community had successfully gained a place.

The available options are very limited.

#### Mental health sector

In the mental health sector, there are very few residences or places available for people with a psychiatric disability who require high-level accommodation and support on a long-term or permanent basis, and many of the existing services already have people waiting for a vacancy. There are only 114 LHD-operated or funded community residential beds across NSW that provide 24/7 support, and 40 per cent of these are for specific populations.

Of concern, our inquiry indicates that:

- The current provision of long-term highly supported accommodation in the mental health sector is insufficient to meet existing demand, let alone the conservatively estimated one-third of people currently in mental health facilities who could be discharged if appropriate options were available.
- The distribution and availability of this accommodation is not equitable across NSW less than half of the LHDs have community residential services.
- Health does not have an accurate state-wide picture of the community residential services that it provides or funds through LHDs. Each of the LHDs have information about the services in their own districts, but there is no consistent overarching system for managing vacancies, and there is no systemic focus in Health on the availability, gaps, or management of the community residential services its LHDs operate or fund across NSW.

We have found that many of the LHD-operated community residential services are intended to be temporary accommodation for individuals who require a longer period of rehabilitation until they can transition to more independent accommodation. However, it is clear from our review and consultations that temporary or transitional accommodation does not meet the needs of individuals who require long-term disability support – including the majority of people in our file review.

In our consultations, we heard that the effectiveness of the existing community residential accommodation places that are designed to provide transitional support is reduced by the lack of 'downstream' long-term and intensively supported accommodation options. Many mental health staff told us that the existing community residential accommodation places can work well for those who gain entry, but they tend to have very little throughput, and do not consistently have a rehabilitation or recovery focus.

Our inquiry has also found that the availability of community residential services in NSW is being constrained by the closure or impending closure of a number of the existing residences or beds. LHDs advised of closures as a result of insufficient resources to undertake property repairs or to replace a staff member on maternity leave, and impending closures related to the end of temporary funding. We noted that few of the mental health NGOs receive funding to deliver 24/7 accommodation support. In our consultations, NGOs reported that they have not had a real increase in funding for many years, affecting their capacity to provide higher levels of support to individuals when needed.

#### **Disability sector**

Importantly, while the current provision of appropriate community-based accommodation options for people with psychiatric disability in the mental health sector is insufficient to meet existing demand, the disability sector provides very few alternatives.

The disability sector has a much larger number of long-term and highly supported accommodation options, including more than 4,000 beds in ADHC-operated and funded group homes. However, few of the highly supported accommodation options are currently available to people with a primary diagnosis of mental illness and/or people in mental health facilities.

For the reasons we have outlined in this report, this is because they very rarely meet the set eligibility criteria in relation to primary diagnosis or location; and/or because there are very few places available. This includes supported accommodation under ADHC's *Allocation* policy; the ISP; the CJP; the YPIRAC program; and the Boarding House Relocation Program.

ADHC, via *Stronger Together*, has increased, and is continuing to expand, the number and range of supported accommodation places for people with disabilities. However, the existing ADHC policy exclusion means that the additional places will not typically be available to people with psychiatric disability, even if they meet the criteria of the DSA.

We recognise that, despite the increased funding of the disability sector in NSW, demand for supported accommodation greatly exceeds supply. ADHC has indicated that, according to modelling completed in 2011, 'at the end of ST2 there will still be a residual unmet demand of 2,263 places, the majority of which is for 24/7 services'.<sup>72</sup>

ADHC has advised that the inclusion of people with a primary diagnosis of mental illness on its register for supported accommodation 'is not sustainable without further growth to the system', and has proposed that 'NSW Health needs to grow an accommodation support response that is closely linked to its community mental health services in consultation with ADHC and the funded sector.'<sup>73</sup>

In response to our draft report, the Department of Family and Community Services (FACS) advised that '[g]reater integration of mental health services with existing disability service models would

<sup>72</sup> ADHC advice, 22 June 2012.

<sup>73</sup> *Ibid.* 

be needed to enable appropriate care to be provided on a wider scale to people with psychiatric disability. This however, has significant resource implications.' The department advised that '[w]ithin current resources, directing support to assist more people with psychiatric disability would therefore result in removing services from other people with a disability who are in need.'74

FACS indicated that there is 'potential to meet some needs through the existing service system, however this will rely on the provision and links with specialist mental health service support, close alignment of services and adequate resources. There will also be value in exploring new models of support.'<sup>75</sup>

We appreciate that there are considerable resource implications involved in enabling people with a psychiatric disability to have equitable access to services provided under the DSA, including supported accommodation. However, it is clear from our inquiry that this must occur, and that there is a need for ADHC and Health to work collaboratively – in the context of the DSA, person-centred approaches, and planning for the NDIS – to negotiate the provision of support, and allocation of resources, to individuals whose service needs go across both agencies.

### HASI is a good model, but it does not currently provide sufficient support

HASI was highly commended by people in our consultations as an effective model of supported accommodation and agency partnership. However, we heard that in many areas the number of HASI places is insufficient to meet demand, with long waiting lists.

This information corresponds with advice provided by the (then) NSW Government in its August 2010 submission to the Productivity Commission. The submission estimated that the supply of HASI services at that time met about 50 per cent of demand. Since then, 39 packages have been added. We note that only four per cent of available HASI packages provide support for up to eight hours per day – the maximum support currently possible under the HASI program.

In addition, we were told in our consultations that the maximum level of support available under HASI is insufficient to meet the needs of some people with severe and chronic mental illness and/or who have complex needs. Our file review supported this information – the majority had been identified as requiring more than eight hours of support per day, and three people referred to HASI had either been declined because their needs were too high, or had a trial placement that failed for the same reason.

The (then) Government's submission to the Productivity Commission indicated that HASI provides support up to, and including, Level C in the *Framework for Housing and Accommodation Support*. However, this does not appear to be the case. In the framework, Level C involves 24/7 non-acute care of a short to medium-term duration; and Level D involves support for 8-16 hours per day, 5-7 days per week over the medium to long-term – neither of which are currently available under HASI. A small number of community residential services provide this higher level of support, but these places are not delivered under the HASI program.<sup>77</sup>

Our findings confirm the importance of the intended work by NSW Health under the National Partnership Agreement on Mental Health to expand HASI in NSW to include 48 packages of 16 to 24 hours per day support ('HASI Plus'). These packages will roughly correspond to Level B (X-HASI) and Level C in the framework.<sup>78</sup>

<sup>74</sup> FACS advice, 18 September 2012.

<sup>75</sup> *Ibid.* 

<sup>76</sup> In August 2010, there were 1,096 funded HASI packages across NSW. As at July 2011, there were 1,135 places.

<sup>177</sup> In August 2012, NSW Health advised that the apparent discrepancy is due to the need to provide a nationally comparable hourly rate to estimate levels of service need. Service modelling was based on the Victorian contract rate rather than actual HASI data.

<sup>78</sup> NSW Health advice, 8 August 2012

In our consultations, concerns were raised with us about the focus in the current HASI packages on single occupancy accommodation. We heard that single occupancy accommodation can be isolating for some people, particularly those used to living with others; and that the focus on this model limits the choice of individuals.<sup>79</sup>

In response to our draft report, NSW Health advised that the new HASI Plus packages will be provided as a direct partnership between Health and NGOs, and provide both accommodation and accommodation support. The tender specifications will include requirements for a mix of separate and 'cluster type' arrangements, which 'will reduce the risk of social isolation for these individuals.<sup>80</sup>

#### There needs to be a wider range of accommodation and support options

It was evident from our file review that there is a need for a range of community-based accommodation and support models for people with severe mental illness and associated disability, as well as flexibility in the system to respond to changing needs. Mental health staff also consistently told us that the range of community accommodation and support options needs to expand in order to give individuals real choices and to facilitate the discharge of people to less restrictive options.

We heard that the available options have decreased with the closure of a number of licensed boarding houses, and that these options have not been replaced with alternatives. Mental health staff told us that they see a need for quality hostel-type accommodation that provides on-site supervision and access to support services; such as the supported accommodation hostels that operate in Queensland under an accreditation and registration system.

Our inquiry has also highlighted the lack of community-based accommodation and support options for people with acquired brain injury. This dearth of options for people with ABI was noted by mental health staff in both metropolitan and regional areas, particularly in relation to 24/7 accommodation support. This information is consistent with the findings of numerous reports over many years.<sup>81</sup>

In our file review, we noted difficulties in identifying potential options for the people with ABI, with generally unsuccessful referrals for supported accommodation to ADHC, and to brain injury services that do not currently provide accommodation. The cause of the ABI of the people in our file review tended to be related to the side-effects of psychotropic medication, or alcohol or drug use. As a result, they do not have access to the Lifetime Care and Support Scheme. We note that people with ABI are part of the target group for the DHASI program, but this is limited to drop-in support of up to 35 hours per week.

Our inquiry points to the need for greater flexibility and innovation in the accommodation and support models that are developed to meet the needs of people with severe mental illness and associated disability, and highlights the importance of person-centred and individualised approaches.

Information provided by the LHDs indicate that increased flexibility in funding arrangements has enabled NGOs to both explore alternative and innovative support options to meet the needs of individuals, and to temporarily fill identified gaps. This has included the use of surplus HASI funds to provide step-up and/or step-down services to clients and to extend support to 24/7.

<sup>79</sup> In response to our draft report, NSW Health advised that there are examples of shared occupancy accommodation in HASI, but 'the likelihood of this occurring will also be influenced by the social isolation of some consumers' (as it would need to be initiated by two people seeking this arrangement). In addition, Health noted that there is 'anecdotal evidence that some stakeholders perceive that HASI will not support shared occupancy arrangements, so this is not always pursued.' NSW Health advice, 8 August 2012.

<sup>80</sup> NSW Health advice, 8 August 2012.

<sup>81</sup> For example, NSW Government (May 2011) Care and Support Pathways for People with an Acquired Brain Injury: Referral and Service Options in NSW; and the Agreement on the Interagency Care and Support Pathway for People with an Acquired Brain Injury (August 2008) between Housing NSW, ADHC, NSW Health and the Lifetime Care and Support Authority.

It is clear that no one model of accommodation support suits everyone, and that the accommodation preferences of people with psychiatric disability are as diverse as people in the broader community. Living in supported accommodation with others does not suit everyone; nor does living alone. It is important that there is a range of accommodation and support models available, including a range of highly-supported options.

Consistent with this view, and in response to our draft report, FACS advised that people with severe mental illness and complex needs 'are not an homogenous group with homogenous needs and service models and systems should reflect this diversity'. The department noted the need for a range of responses that can be tailored to individual needs, and indicated that there 'will also be value in exploring new models of support.'82

#### Community care packages appear to be infrequently considered or accessed

The 2005 NSW Interagency Action Plan for Better Mental Health notes that, historically in NSW, many people with a psychiatric disability have not used the support services that have been established to assist them to live independently, such as HACC services.

This was also reflected in our file review and consultations. Only two people had been linked to in-home support services, whether through the HACC or community aged care programs. HACC services were rarely considered by mental health staff and others as a potential option for individuals, with or without additional supports such as HASI.

HACC services alone are unlikely to provide sufficient support to meet the needs of the majority of people in our file review. However, these services can be a valuable component in a package of supports or wraparound services that could assist people with psychiatric disability to live successfully in the community, in addition to clinical and disability supports through programs such as HASI.

#### It is difficult for mental health inpatients to access residential aged care

We identified that people with mental illness aged 65 years and over have difficulty gaining admission to residential aged care facilities. Mental health staff told us that:

- It is difficult to get an ACAT assessment, particularly for involuntary patients. As a result, staff have had to apply for guardianship to enable individuals to become voluntary patients with the consent of the appointed guardian.
- Few residential aged care facilities are willing or able to accept mental health inpatients, particularly those with historical or current challenging behaviour, due to the perceived or actual risk to other residents.

The guidelines relating to aged care assessment and approval of people with mental illness indicate that ACAT assessment and approval is only appropriate if the intensity, type and model of care is the most appropriate to meet the person's needs (including that the person has predominately aged care needs; the person's mental health condition is stable; and community mental health services continue to provide collaborative care for those people with significant or unstable psychiatric symptoms).<sup>83</sup>

Our file review confirmed some of the reported challenges in getting mental health inpatients appropriately accommodated in residential aged care facilities. Files indicated discussions with ACAT staff regarding the need to explore options for the person to gain voluntary admission status to enable assessment to occur; recorded unsuccessful attempts to have individuals with some aggressive behaviour placed in residential aged care; and identified people whose trials in residential aged care had failed due to behaviour that was linked to their mental illness.

<sup>82</sup> FACS advice, 18 September 2012.

<sup>83</sup> Department of Health and Ageing (June 2010) Assessment and approval of people with a mental illness.

However, we were advised of successful transitions to a few residential aged care facilities that have developed expertise in supporting people with mental illness. Mental health staff in some districts told us that they have worked hard to establish and maintain relationships with staff in key residential aged care facilities to support the transition process and assist with future referrals. We heard that this includes mental health staff providing follow up support for several weeks to people who had moved to residential aged care.

Two initiatives in particular were highlighted as positive endeavours aimed at supporting the transition of older people with high-level, complex and persistent psychiatric symptoms into long-term residential and community care:

- Two organisations have been funded under the Mental Health Aged Care Partnership Initiative
  to operate pilot services within residential aged care facilities in metropolitan Sydney. The
  initiative includes purpose-designed Special Care Units within the residential aged care
  facilities; specialist consultation and case management support from Specialist Mental Health
  Services for Older People; and supported transition to mainstream residential aged care
  facilities or community care.<sup>84</sup>
- Transitional Behavioural Assessment and Intervention Services (T-Basis) units provide a
  transitional non-acute inpatient service model of care over the short to medium term for older
  people with severe and persistent challenging behaviours associated with dementia and/or
  mental illness. Outreach workers are a key element, to maintain linkages with residential aged
  care facilities and to enhance the capacity of these facilities to provide appropriate care.<sup>85</sup>

The introduction of Support Facilitators under the Commonwealth Government's Partners in Recovery Initiative provides a useful opportunity to improve the access to residential and community care for people with severe and persistent mental illness and complex needs who are over 65 years. There would be considerable benefit in ensuring that aged-related accommodation and supports are part of the focus of Support Facilitators, including enabling:

- the provision of more appropriate and integrated support for these individuals, across Commonwealth-funded services and programs; and
- a reduction in the number of people aged over 65 years who remain in mental health facilities
  due to barriers in accessing residential or community aged care; and improved availability of
  acute inpatient support for those that need it.

## 4.3 Interagency coordination

National and NSW mental health plans and agreements emphasise the importance of a whole-of-government approach to supporting people with severe mental illness in the community, and coordinated service delivery and effective interagency communication across government agencies and NGOs.

At the time of our review, key NSW interagency agreements relating to supporting people with mental illness were in a state of flux. The NSW Interagency Action Plan for Better Mental Health had concluded in 2010; the JGOS was in the process of being replaced; and the ADHC/ Health MOU relating to people with dual diagnoses of intellectual disability and mental illness had been released for approximately six months.

<sup>84</sup> NSW Health (2011) Evaluation of the Mental Health Aged Care Partnership Initiative Summary Report.

<sup>85</sup> NSW Health Greater Southern Area Health Service (2011) *Evaluation of the Transitional Behavioural Assessment and Intervention Services (T-Basis) Units Initiative and Model of Care.* Two services are based in the Hunter, two in Southern NSW, and one in South West Sydney.

Our inquiry has reinforced the need for effective interagency coordination and collaboration to minimise barriers to accessing services, enable coordinated and consistent service provision, and facilitate person-centred support.

#### **NSW Health and ADHC**

Staff from both agencies expressed concerns about interagency issues that the ADHC/ Health MOU has been developed to address, including:

- difficulties in getting people with intellectual disability admitted to mental health facilities due to the perception by Health that the person has challenging behaviour rather than mental health needs; and
- difficulties in getting disability services to provide accommodation and support to mental health facility inpatients with intellectual disability, or to accept the discharge of clients of ADHCoperated or funded services who have been admitted for treatment.

The primary concern raised by mental health staff related to the adequacy of ADHC's response to referrals for supported accommodation on behalf of inpatients with intellectual disability or other cognitive impairment. Mental health staff in many districts raised concerns with us about ADHC's focus on intellectual disability and demand for evidence to prove that diagnosis. While the ADHC/ Health MOU indicates that, for the purposes of the agreement, 'intellectual disability' includes people with low cognitive functioning, information provided by mental health staff suggests that this is not reflected in practice.

Mental health staff expressed frustrations about the amount of time that is spent determining which agency is responsible for providing support, including establishing eligibility, rather than focusing on the needs of the individuals.

At the time of our meetings with mental health staff in 2011, there were considerable variations in the existence and quality of joint forums or regular meetings between ADHC and Health across regions/LHDs. Few of the districts at that time had established the local forums required by the ADHC/Health MOU, and mental health staff indicated that the effectiveness of the existing meetings was limited by ADHC not sending staff with sufficient seniority or authority.

We note that effective implementation of the ADHC/ Health MOU provides the means to resolve some of the issues raised in our consultations about interagency work, including a requirement that senior managerial and operational staff from each agency attend the local forums.

Our consultations with ADHC regional staff occurred some months after our meetings with mental health staff. We found that arrangements relating to local forums appeared to be more fully formed by early 2012 than they were in mid-2011, and ADHC staff tended to report positive relationships at a local level with health staff. Several ADHC regions reported joint staff training and information sharing sessions that had occurred since the roll out of the MOU, which had helped to improve staff understanding of roles and responsibilities across both agencies.

ADHC staff indicated that community mental health support for people with mental illness living in disability services was limited in most regions, and would typically only be provided if the person was under a Community Treatment Order.

## **NSW Health, ADHC and Housing NSW**

In the main, both mental health and ADHC staff indicated that they had a good working relationship with Housing NSW, while noting the limited availability of social housing in some areas, including the north coast and regional areas like Narrabri.

Mental health staff reported positive responses by Housing NSW to priority housing requests, transfer, or reinstatement of tenancies after hospitalisation. However, a small number reported difficulty in getting Housing to reconsider individuals who had a history of behaviour problems in social housing when unwell, such as setting fires.

We saw examples of good interagency work between mental health and housing staff in our file review, including written commitments by community mental health to provide ongoing clinical support to facilitate applications for priority housing, and positive responses by Housing NSW to accommodation requests.

ADHC regional staff indicated that cross-agency work with Housing had improved since both agencies had been brought under FACS. In response to our draft report, FACS advised that, since amalgamation of the separate agencies, the department has worked on better linking services for common client groups. 'This has resulted in for example development of improved links between the disability and public housing services delivered by FACS.'86

## Interagency work between ADHC and Health relating to people with psychiatric disability

As noted in section 4.2.2, the NSW Government's response to the draft Productivity Commission report supported the adoption of an inclusive, coordinated approach within the NDIS in relation to people with psychiatric disability, and emphasised the need for:

- a joint strategy involving the mental health and disability sectors, to build cross-sector capacity and skill sets and a joint understanding of roles and responsibilities; and
- a collaborative, person-centred approach to planning to determine the sector(s) that best meet the identified needs of individuals, and to further determine their respective roles and responsibilities.

ADHC's advice to us echoes this view, stating that '[c]urrent practice leads to individuals being managed by one sector; either disability services or mental health services.'87 ADHC advised that a more coordinated and collaborative approach is required to deliver more responsive person-centred care and to appropriately meet the needs of individuals; and that, where service needs are shared across agencies, resource allocation should be negotiated to ensure the most appropriate support is provided.

This position is in line with the ADHC/ Health MOU, but that agreement only relates to people with intellectual disability and mental illness. Where a person has a primary diagnosis of mental illness and a psychiatric disability, there is no such joint strategy or collaborative and person-centred approach between the disability and mental health sectors. Responsibility for support typically remains with one sector only – the disability sector for people in the Boarding House Relocation Program, and the mental health sector for everyone else.

<sup>86</sup> FACS advice, 18 September 2012.

<sup>87</sup> ADHC advice, 5 April 2012.

Our inquiry affirms that there is a critical need to extend the positive joint approach to support between the disability and mental health sectors promoted by the ADHC/ Health MOU to people with a primary diagnosis of mental illness and psychiatric disability.

While the two key interagency agreements involving ADHC and Health that relate to people with mental illness – the ADHC/ Health MOU and the *Housing and Mental Health Agreement* – apply to specific target groups, they provide a useful platform for the development of a joint strategy to support people with psychiatric disability. Both agreements include a focus on:

- the delivery of coordinated, collaborative, flexible and client-focused services;
- ongoing, structured communications with partners, with emphasis on coordination at the local level;
- improving cross-agency referral pathways and processes;
- understanding the roles and responsibilities of partners and other providers; and
- the development of local mechanisms to undertake joint client-focused planning; identify and resolve local and broader issues that impact on service provision; and escalate issues that cannot be locally resolved.

Given the significant role of NGOs in the provision of disability support in both sectors, there is a strong argument for their inclusion in any joint agreement relating to support for people with psychiatric disability. NGOs are not formally involved in the ADHC/ Health MOU, and their invitation to local forums is optional.

In relation to broader interagency coordination and support for people with psychiatric disability, we note that the NSW Interagency Action Plan for Better Mental Health concluded in 2010. The new Mental Health Commission Act empowers the Commission to develop a new strategic interagency plan for NSW.<sup>88</sup>

There are multiple high-level cross-agency committees that include a focus on improving outcomes for people with mental illness who have complex needs and/or dual diagnoses, including:

- The Mental Health Senior Officers' Group comprising the departments of Health, FACS, Premier and Cabinet, Attorney General and Justice, Education and Communities, and Treasury.
- The ADHC/ Health Senior Officers' Group which includes the Joint Committee on Intellectual Disability Mental Health, which oversights implementation of the ADHC/ Health MOU.
- The Housing and Mental Health Senior Executive Group comprising Health and FACS, and involving oversight of the Housing and Mental Health Agreement.

It will be important for any agreement developed between Health and ADHC relating to services and support for people with psychiatric disability to have effective reporting and governance arrangements, including appropriate linkages to the ADHC/ Health Senior Officers' Group.

<sup>88</sup> The NSW Mental Health Commission started on 1 August 2012.

## **Chapter 5 Accommodation support models**

# 5.1 What the research says about community accommodation support models

Research in Australia and overseas on models of community-based accommodation support for people with severe mental illness and associated disability indicates that housing approaches have evolved from a custodial and 'medical-model' approach, towards supported housing. In the past decade, models of accommodation support have tended to shift from continuum or 'transitional' housing towards permanent supported housing.

The transitional housing model provides for individuals to move to less intensively staffed environments as their level of functioning improves. Transitional accommodation models include some of the community residential services in NSW; and a range of community care units and residential rehabilitation services in other Australian states.

Research in NSW and other jurisdictions has identified problems with the transitional model, including that there is an inherent lack of housing stability; not everyone is able to successfully move through the continuum; not all parts of the continuum are available; and there is a lack of consumer choice of housing options.<sup>89</sup>

The permanent supported housing model has increased in popularity in recent years, and addresses many of the concerns that have been associated with transitional accommodation and support. This model provides individuals with permanent housing into which staff support and treatment – wraparound services – can be introduced as needed. Models of supported housing include HASI and HASP in Australia, and 'Housing First' in the US.

Research studies have found that secure, supported housing provides better outcomes for people with mental illness, and have identified that key features of successful models include:

- consumer choice and control over housing and support, or as close as possible to it;
- individualised and flexible support that is provided for as long as necessary; and
- provision of accommodation that is not dependent on the treatment provided, or the person's eligibility for public housing.<sup>90</sup>

Importantly, the research on community-based accommodation and support for people with severe mental illness and associated disability points to the need for a spectrum of options, comprising a full continuum of support.

The Productivity Commission's final report from its Disability Care and Support inquiry also pointed to the need for a spectrum of accommodation options. The Commission noted that, while Australian jurisdictions have developed a range of specialised, community-based residential services to replace the historical functions of standalone psychiatric hospitals, 'this process is incomplete, and ... there

<sup>89</sup> Chopra P, and Hermann, H E (2011) 'The long-stay outcomes and unmet needs of a cohort of former long-stay patients in Melbourne, Australia', in *Community Mental Health Journal*, 47, 531-541; Freeman, A, et al (2003) *High Support Accommodation for People with Psychiatric Disabilities*; Leff, H S, et al (2009) 'Does One Size Fit All? What We Can and Can't Learn From a Meta-analysis of Housing Models for Persons with Mental Illness' in *Psychiatric Services*, Vol 60, No 4, 473-482; Nelson, G, (2010) 'Housing for People with Serious Mental Illness: Approaches, Evidence, and Transformative Change', in *Journal of Sociology & Social Welfare*, Vol XXXVII, No 4; and Rog, D J (2004) 'The evidence on supported housing', in *Psychiatric Rehabilitation Journal*, 27(4), 334-344.

<sup>90</sup> Chopra and Hermann op. cit; Nelson op. cit; and Rog op. cit.

are major disparities between the states and territories in the level and mix of psychiatric beds provided to their populations'.<sup>91</sup>

The mix of community-based accommodation includes step-up/ step-down services; transitional residential rehabilitation services; and supported housing. Appendix 5 provides a summary of community accommodation support models in Australia.

## 5.2 Relevant planning work

The findings of our inquiry regarding the need for a broad range of community accommodation support options for people with severe mental illness and associated disability are consistent with the findings of Australian and international research studies; the findings and recommendations of major mental health-related inquiries in Australia; the stated intentions of Health plans in NSW, including the *Framework for Housing and Accommodation Support*; and current mental health planning activity underway in NSW and nationally.

A National Mental Health Service Planning Framework is being developed by NSW for the Commonwealth, under the Fourth National Mental Health Plan. The framework will establish targets for the mix and level of the full range of mental health services: including acute; long stay; 'step up/ step down'; and supported accommodation services; as well as ambulatory and community-based services. The framework is to be supported by flexible and innovative funding models.

A Sector Development Benchmarking Project being undertaken by the Mental Health Coordinating Council (MHCC) and funded by NSW Health will inform the development of the framework. The project will establish population planning targets against mental health service types; including the number of supported accommodation places that are required per 100,000 of population, adjusted for specific geographic catchment areas. The work will also assist with sector development planning, including identification of required resources, and access and equity gaps.<sup>92</sup>

Information from our inquiry highlights the necessity of this work. We have identified a critical undersupply of long-term highly supported accommodation for people with severe mental illness and psychiatric disability in NSW, and inequitable distribution of, and access to, those places that exist. In addition, there does not appear to be a clear, aggregated state-wide picture of what places are available and what is needed.

## 5.3 Person-centred and individualised funding approaches

The focus in NSW on supported housing, including HASI, is in line with research findings on the success and benefits of those models for people with severe enduring mental illness and associated disability. Of significance, we note that the research emphasises the critical link between personcentred, individualised, and flexible approaches, and improved outcomes for individuals. This is consistent with the current and planned disability sector reforms in NSW and nationally, including the proposed NDIS.

Person-centred and individualised funding and support packages for people with mental illness already exist in a number of jurisdictions:

• Western Australia is undertaking a four-year pilot project to provide individualised support packages to 100 people with a severe and persistent mental illness who have been in mental

<sup>91</sup> Productivity Commission (August 2011) Disability Care and Support, Appendix M: The Intersection with Mental Health, p.M7.

<sup>92</sup> Mental Health Coordinating Council (2011) Annual Report 2010-2011.

- health inpatient facilities for an extended period. The packages are linked to the provision of 100 housing units in metropolitan and regional areas, and tailored support.
- Self-directed funding for support of people with psychiatric disability already exists in the UK, and in some regions of Canada and the US. The MHCC has reported that the outcomes of self-directed support pilot programs involving people with psychiatric disability 'are overwhelmingly positive.'93

The Commonwealth Government's intended introduction of Support Facilitators under the 2011-12 federal budget appears to be a step towards individualised support packages for people with severe and persistent mental illness. However, the funding allocation for this program over five years of under \$3,000 per person per year means that it is highly unlikely that the flexible support packages will extend to high levels of accommodation support.

The MHCC has noted that the introduction of self-directed care models for people with psychiatric disability would require 'a complete transformation of the service system'. Importantly, this includes shifting away from block funding of NGOs, and providing the type of services that clients want, in the way and at the times that they want them. This is a critical element of the reforms underway in the disability sector in NSW – the Government is leading widespread transformation of the disability service system to enable individuals to have as much direct control as possible over their supports.

The MHCC has reported that the NGO mental health sector is currently not involved in the discussions or consultations regarding person-centred and individualised funding approaches in the NSW disability sector. The current demarcation between the health and disability sectors in the provision of support to people with psychiatric disability means that these individuals are largely excluded from the personalised funding reforms.

Significantly, the MHCC has noted that if the NGO mental health sector is not involved, or engages late, in the disability reform discussions, 'there is a risk that people with a psychosocial disability will be an afterthought in terms of the system design, even if they are ultimately eligible for self-directed care packages.'95 This is particularly important in light of the Government's indications that a key part of the disability sector reforms is about becoming ready for the NDIS.

It is positive that the National Mental Health Service Planning Framework is to be supported by flexible and innovative funding models. Information provided by LHDs indicates that, where there is flexibility in the funding arrangements, NGOs develop and implement innovative accommodation and support models that are designed to meet the particular needs of individuals, and to fill identified and localised gaps in services.

It is outside the scope of our inquiry to seek to specify what mix of mental health services, including accommodation services, NSW should have. The work underway in NSW to inform the National Mental Health Service Planning Framework will be important in this regard. However, this inquiry clearly indicates the need for an increased supply and range of supported housing options that provide on-site support for 16 to 24 hours per day, and for services and support for people with psychiatric disability to be driven by flexible, person-centred and individualised approaches.

<sup>93</sup> Mental Health Coordinating Council (November 2011) Self-Directed Funding and the Community Managed Mental Health Sector: Opportunities and Challenges discussion paper, p.13.

<sup>94</sup> Ibid., p.17.

<sup>95</sup> Ibid., p.28.

### **Chapter 6 The need for change**

### 6.1 FACS' response to our draft report

Given the problems identified in this inquiry regarding agency demarcation, we welcomed FACS' decision to provide a whole-of-department response to our draft report (see Attachment 1).96

FACS' response recognises the multiple service needs of many people with psychiatric disability, including the need for effective community mental health and disability support, and stable and secure housing. Consistent with our report, the department's response emphasises the importance of delivering person-centred and integrated support across mental health and disability services, and notes the opportunities presented by the NDIS in this regard.

However, outside of the prospective NDIS, the FACS response does not indicate what can or should be done to resolve the critical issues in our report – including the exclusion of people with psychiatric disability from services under the DSA. The response focuses on why the department considers that its agencies are not well placed to support people with severe mental illness and associated disabilities, and the reduced services available for other people in need if support is directed to people with psychiatric disability.

It is difficult to see how FACS' response has been informed by the key findings of our inquiry. Importantly, the department has not acknowledged the eligibility of people with psychiatric disability for services under the DSA, and the continuing infringement of the rights of these individuals. We appreciate the existing resource constraints; however, it is unacceptable to trade-off the rights of people with psychiatric disability against those of others.

It is disappointing that FACS has not identified key actions and opportunities that may be taken now to work towards addressing the issues in this report and improving the outcomes of the people with psychiatric disability who are the focus of this inquiry. In this regard, we note that the department's response does not refer to the opportunities that exist in the current disability sector reforms under *Stronger Together* or the strategic plan to be developed by the new Mental Health Commission.

We agree that the NDIS provides a valuable opportunity, but it is important that necessary actions are not delayed until the future start of the scheme. There is critical work that FACS and Health ought to undertake now to improve support to people with psychiatric disability that is consistent with the intended operation of the NDIS, and compatible with the reform agenda under *Stronger Together* and the vision behind the creation of the Mental Health Commission.

#### 6.2 Conclusion

Mental health legislation and United Nations principles require the care and treatment of people with mental illness to be provided in the least restrictive environment possible. However, our inquiry has found that many people who are living in mental health facilities do not clinically need to be there. The conservative estimate is that around one-third of people currently living in mental health facilities in NSW could be discharged to the community, if appropriate accommodation and supports were available.

The impact of this situation is significant. It reduces the already limited capacity of mental health facilities to admit and retain people who are acutely unwell and need intensive clinical support, and to move patients from acute units to less intensive rehabilitation units. It also adversely affects the use of rehabilitation units, turning them into long-stay accommodation instead of transitional places focused on clinical rehabilitation and recovery.

<sup>96</sup> FACS provided the response on 18 September 2012.

The impact on the individuals is also considerable. Some are inappropriately accommodated in acute or other secure units, and many have been in hospital so long that they have developed institutionalised behaviours.

We have found that there are many factors that impede the effective discharge of mental health inpatients to the community, including inadequate discharge planning by mental health staff; limited capacity of community mental health teams to provide sufficient and timely support; insufficient supply and range of highly supported housing in the community; and limited access of people with psychiatric disability to services and supports provided under the DSA.

Many of the problems identified in this inquiry relating to discharge planning and gaps in community-based accommodation and support for people with enduring psychiatric disability have been identified in multiple inquiries and reports over many years. It is imperative that concerted action is taken now to address these critical gaps and to ensure that mental health facilities are not seen as appropriate ongoing accommodation for people who are clinically well enough to be discharged into the community. Our file review has identified people aged 24 and 25 years who have already been in hospital for over five years. It is unacceptable that these individuals may be facing a similar future to others in our file review who were admitted to hospital as teenagers and only left when they were discharged to aged care facilities over 40 years later.

Our inquiry reinforces the importance of the recently announced funding under the National Partnership Agreement on Mental Health to enable NSW Health to expand HASI to include support for 16 to 24 hours per day. The 48 packages provide a useful starting point for the provision of improved community-based support to people with enduring psychiatric disability, and for an increased focus on highly flexible, person-centred, and individualised approaches. The planning for the delivery of these packages also provides a valuable opportunity for Health to review the systems in place to facilitate this work – including the current use and effectiveness of rehabilitation beds and community residential services.

Central to this inquiry are the critical problems we have identified regarding support for people with psychiatric disability, and their access to services provided under the DSA. It is of concern that, while these individuals are included in the target group for services under the DSA, they do not have consistent access to the full range of services, including supported accommodation, primarily due to the demarcation of responsibilities between ADHC and Health.

People with a disability that meets the criteria of the DSA should be eligible for services and supports consistent with that legislation – irrespective of how that disability was acquired, what their primary diagnosis is, or where they are living. However, for people with psychiatric disability who have a primary diagnosis of mental illness, this is not currently the case.

The reform work currently being undertaken in the disability sector to develop person-centred and individualised approaches and to prepare for the proposed NDIS provides a prime opportunity for ADHC and Health to revise the existing arrangements, and to deliver greater consistency, equity, and choice to people with psychiatric disability regarding disability supports.

Our inquiry points to the critical need for ADHC and Health to develop a joint strategy, and a consistent and collaborative approach between the disability and mental health sectors, in the provision of support to people with a primary diagnosis of mental illness and a psychiatric disability that meets the criteria of the DSA. The focus must be on the identified needs of the individual with a psychiatric disability, and a person-centred approach to meeting those needs.

However, we recognise that the demarcation between ADHC and Health relating to support for people with psychiatric disability is longstanding, and may not be easily resolved through good leadership and goodwill. If matters relating to cross-agency work cannot be resolved, government may need to consider whether a change to the existing agency clusters would bring mental health and disability closer together.

### Recommendations

## Joint strategy to provide appropriate mental health and disability support to people with psychiatric disability

- FACS and Health should develop a joint strategy on the provision of support to people with a psychiatric disability that is consistent with the *Disability Services Act 1993* (DSA). The strategy should:
  - a) be developed in consultation with the NSW Mental Health Commission;97
  - reflect a coordinated, collaborative and person-centred approach by the disability and mental health sectors to providing services and support to best meet the identified needs of individuals;
  - c) include the NGO sector as a key partner; and
  - d) include clear reporting and robust and effective governance arrangements.
- 2 FACS and Health should:
  - a) develop a joint strategy to increase the availability and range of long-term and highly supported (16-24 hours per day) housing options for people with enduring psychiatric disability; and
  - b) provide regular public reports on the implementation of the joint strategy, including details of the increase in the number and range of long-term and highly supported housing options, by region.

### Access to disability services

- 3 ADHC should immediately amend its *Allocation of Places in Supported Accommodation* policy so that:
  - a) people with a primary diagnosis of mental illness and a disability that meets the criteria of the DSA are eligible for a place on the Register of Requests for Supported Accommodation; and
  - b) people who are unsuccessful in obtaining a place on the Register of Requests for Supported Accommodation are provided with written reasons for the decision, and advice as to the available options for requesting a review of the decision.
- 4 ADHC should develop criteria to ensure that eligibility for disability services includes an assessment of an individual's functional need, and does not rely on their primary diagnosis.

<sup>97</sup> The purpose of consulting with the Mental Health Commission is to ensure that the joint strategy is consistent with the overall strategic plan for the mental health system in NSW that is being prepared by the Commission.

## Action to transition individuals from hospital to appropriate accommodation and support in the community

- 5 Health should review the circumstances of all current mental health inpatients in order to:
  - a) identify individuals who could be discharged with appropriate community accommodation and support; and
  - b) together with ADHC, develop and implement a staged plan to transition those individuals to the community.

### Access to person-centred and individualised support

- ADHC should ensure that people with psychiatric disability, and their representatives, are adequately included in the disability sector consultations and planning under *Stronger Together*, particularly in relation to person-centred and individualised funding approaches.
- In the context of the issues identified in this report, and the disability sector and national reforms, Health should explore options for introducing person-centred and individualised funding approaches to the mental health sector.

### Discharge planning

- Health should conduct a state-wide review, and regular audits, of discharge planning practice in mental health facilities to ensure that:
  - a) practice is in line with relevant policy and legislation;
  - b) decisions regarding support needs and readiness for discharge are informed by recent and accurate information;
  - c) internal factors adversely affecting discharge are identified and addressed; and
  - d) individuals who could be discharged with appropriate community accommodation and support are identified, and action taken to progress their transition to the community.
- Health should provide training and improved guidance to mental health staff regarding discharge planning, including: referral options, eligibility criteria, and appeal mechanisms.

### Mental health systems

- Health should review the adequacy of its current system for transferring individuals to mental health facilities within and across Local Health Districts. The review should include consideration of the role of the Complex Care Committee, and its authority to approve transfers.
- In the context of the issues raised in this report, and broader mental health service planning, Health should review the current use and effectiveness of Local Health District-operated or funded rehabilitation beds and community residential services provided to mental health patients. The review should include, but not necessarily be limited to, consideration of:
  - a) overall capacity and distribution;
  - b) the role of LHDs and NGOs in delivering services;
  - c) whether the services are provided in line with their intended purpose, and achieve their intended objectives;
  - d) whether the support provided reflects a flexible and person-centred approach;
  - e) the adequacy of the current arrangements for identifying and managing vacancies across NSW; and
  - f) the adequacy of the current arrangements for monitoring the operation of the services, and for identifying system-wide gaps in accommodation and support.

### Reporting on recommendations

- In relation to the recommendations that we have directed to their respective agencies, FACS/ ADHC and Health should:
  - a) provide a response to the recommendations by 1 March 2013; and
  - b) provide a progress report on implementation of the recommendations by 31 December 2013.

# Appendix 1: Department of Family and Community Services' response to the draft report\*

All people with mental illness and/or cognitive impairment need to be supported in a way that enables them to live a good life.

The Department for Family and Community Services (FACS) shares your concerns regarding the impact on the lives of people with mental health related disability when service systems are not addressing their needs in the most responsive manner.

FACS concurs with the importance of improving the support for people currently living in mental health facilities who could be discharged into the community, but is also acutely aware of the broad need to improve the availability of community mental health services and to align these services to provide more integrated and person centred supports to people with a range of mental health related complex needs.

The current configuration and priorities of the NSW Family and Community Service system has been structured in response to the decisions of both State and Commonwealth governments and resource constraints that exist for all family and community service systems. As you would be aware, in the context of increasing demand, any shift in priorities has flow on impacts and can mean displacing people who currently access funded support systems within existing priorities. In the case of people with mental illness and complex needs, if increased and broadened supports were to be provided within the currently configured service systems, including social housing and disability services, this would impact on and potentially displace others who access these supports through existing priorities. It is acknowledged that Governments can choose to change the Department's policy settings and priorities.

### The Role of Housing

A stable and secure tenancy works to underpin and strengthen the potential for success of other services that may play a role in stabilising people's health and wellbeing. Studies have shown that Australians moving into stable housing have improved health, lower levels of stress, higher self-esteem and feel safer. Children have also been shown to be happier.<sup>99</sup>

In Australia, the expected ideal is for individuals and families to achieve stability and security of tenure through living in their own home in the private housing market. Where this is not possible a stable and secure home may be provided through social housing. However, the current social housing models of tenancy management rely on the client being able to live in the community independently or with some support, and being responsible for managing their tenancy obligations under the *Residential Tenancies Act 2010*.

Social housing does not itself provide support to individuals and families. For those who are unable to sustain a tenancy without support, which relates to their individual needs including mental health issues, drug and alcohol issues or escaping domestic violence, support programs can be provided. There is significant evidence that programs offering a range of support and coordination with other services, such as specialist mental health services, do assist people with complex needs to sustain their tenancies. The recent evaluation of the Housing and Accommodation Support Initiative (HASI)

<sup>98</sup> Response provided on 18 September 2012.

<sup>99</sup> Australian Housing and Urban Research Institute, *The health, employment and education benefits of public housing*, March 2005 www.ahuri.edu.au/publications/download/rap issue 54.

has shown that with the coordinated accommodation support along with clinical mental health support some 90% of tenants sustained their social housing.<sup>100</sup>

However, in this type of situation, where specialist mental health services are incorporated into the social housing context, there is a point at which the intensity of support required is so great that there is no distinction between social housing and supported accommodation.

Social housing as it is currently configured is not equipped with the skills and capacity to undertake the intensive tenancy management needed for high support needs clients.

The social housing system is responding as best it can to ensure that with the right specialist mental health supports are in place so that people don't need to be living in circumstances where they require intensive and extensive interventions. However, in situations where people do require specialist mental health supports with an intensity that is so great that their capacity to sustain an independent tenancy is severely compromised, the model of incorporating support into social housing is not appropriate.

### **Disability Services**

Ageing, Disability and Home Care (ADHC) currently provides a range of supports to people with a psychiatric disability. This includes supported accommodation for some individuals, for example people with a dual diagnosis of psychiatric and intellectual disability.

Support is also provided to people with a psychiatric disability to live in their own home through Home and Community Care (HACC) services. Analysis of ADHC data has identified that over 750 clients with a primary or secondary psychiatric disability receive HACC services.

Greater integration of mental health services with existing disability service models would be needed to enable appropriate care to be provided on a wider scale to people with psychiatric disability. This however, has significant resource implications. Early findings of a study to analyse the utilisation of FACS services by people with mental illness indicate that Disability Services' clients with a (primary or secondary) psychiatric disability are more expensive – accounting for eight per cent of the client group but 19 per cent of the service costs. Within current resources, directing support to assist more people with psychiatric disability would therefore result in removing services from other people with a disability who are in need.

However, in the most part, existing support models do not meet the needs of individuals with a primary mental health diagnosis. Within the current operational structures, which reflect ADHC's legitimate priorities, the needs of many people with severe psychiatric disabilities and complex needs cannot be met safely and effectively. Much as the mental health system is not equipped to meet the needs of those with other acute disabilities, ADHC's services are not equipped to respond to severe psychiatric disabilities on a wide scale.

FACS also observes that, as with the social housing model, there are limitations of the Disability Services model of supported accommodation for people with psychiatric disabilities. For example, the current model may not be able to respond appropriately to the needs of people with episodic conditions whose support needs fluctuate. During periods of remission or wellness, these individuals may benefit from greater independence than is available within current supported accommodation models, whilst during an acute episode, there may be a need for intensive support.

Significant efforts are being made to enhance ADHC's ability to work with individuals with a dual diagnosis of mental illness and intellectual disability. The Office of the Senior Practitioner has a key role in promoting and monitoring a range of intellectual disability and mental health initiatives. This

<sup>100</sup> Jasmine Bruce, Shannon McDermott, Ioana Ramia, Jane Bullen and Karen R. Fisher, Evaluation of the Housing and Accommodation Support Initiative (HASI): Final Report, September 2012.

includes a Memorandum of Understanding (MOU) with the NSW Ministry of Health, which seeks to promote a safe and coordinated system of care and improve access to, and the effectiveness of, services for people with coexisting mental illness and intellectual disability. Linked to this MOU are initiatives to enhance the skills and knowledge of GPs, nurses and support workers in working with people with a dual diagnosis and to address barriers to access and promote better pathways to care for this group.

The Integrated Services Program (ISP), administered by ADHC, provides coordinated support (accommodation, case management, therapy) for people experiencing multiple and complex needs including mental illness, personality disorder, intellectual disability, drug and alcohol abuse and acquired brain injury. One of the inherent difficulties in working with this group is that formal diagnosis is often unclear or contested, for example, people with atypical psychoses or borderline personality disorders. The ISP provides short to medium term (18 months) interventions with a view to establishing ongoing models of care for people following exit from the Program. Via an innovative partnership between ISP and HASI, support packages for clients with mental illness and other complex needs have been enhanced through top-up funds enabling NGOs to provide effective supports. Essential in this work is the development of individually tailored support and accommodation models in line with specifically identified needs.

## Children and mental ill-health – the relationship with Out of Home Care

FACS is acutely aware of the strong relationship between unmet mental health needs among parents and the presence of children in the child protection system. Of the parents at risk of losing their children who were admitted to a Community Services program to address their needs, over half had a mental health problem.<sup>101</sup> As evidenced by an independent evaluation of this program, whilst better support for these parents in community mental health services could allow children to remain with or return to their parents, at present too many parents do not receive sufficient support.<sup>102</sup>

Other studies have shown that this figure for early intervention work is also reflected in removals of children where a parent had identified mental health concerns. In two studies (one being in NSW) of parents with intellectual disability high rates of co-morbidity between intellectual disability and mental health was found amongst the parents.<sup>103</sup>

The limitations of community based mental health services, and of tools available to the court to direct parents into the use of services when they exist, is a significant factor in the removal of children and the burgeoning numbers of children and young people in out-of-home care (OOHC).

This has significant implications for the child, the parents and other family members. If a child is in a family with a parent receiving appropriate specialist mental health support, not only are they more likely to be able to stay in their home and connected within their family, over time as the child transitions to adulthood they become part of the ongoing support and care system for the parent, which in turn reduces the demand on the state. Conversely, if the child is removed and placed in out of home care, studies both in this State and elsewhere establish that outcomes across many aspects of their life are likely to be poor, creating increased demand for state support in future.

102 Ibid.

<sup>101</sup> Social Policy Research Centre, University of New South Wales, The Evaluation of Brighter Futures, NSW Community Services Early Intervention Program, September 2010 http://www.community.nsw.gov.au/docswr/\_assets/main/documents/brighter futures evaluation4.pdf.

<sup>103</sup> Glaun DE and Brown PF (1999) 'Motherhood, intellectual disability and child protection: characteristics of a court sample' *Journal of Intellectual and Developmental Disability* 24 (1): 95-105; McConnell D, Llewellyn G and Ferronato L (2000) *Parents with a disability and the NSW Children's Court*, University of Sydney.

It is therefore critical that the needs of families are better met through the delivery of community based mental health services that are person centred and, in family circumstances, appropriately cognisant and responsive to the needs of the children or young people. Your report refers to a 'paucity of available and adequate clinical support'104 for people with significant mental health problems living in the community and we would welcome greater consideration of the implications of this finding for the outcomes for individuals, the children of adults living with mental illness, the broader family and communities more generally.

### People with mental health related complex needs living a better life

As highlighted by the challenges noted above, to support people with mental illness and complex needs to live a better life, a range of responses are required that can be tailored to individual needs. These will have regard for the mental health condition, family circumstances and personal preferences, to deliver a person-centred service. People with severe mental health illness and complex problems are not an homogenous group with homogenous needs and service models and systems should reflect this diversity.

There is potential to meet some needs through the existing service system, however this will rely on the provision and links with specialist mental health service support, close alignment of services and adequate resources. There will also be value in exploring new models of support.

As you recognise in your report, the NDIS provides an opportunity to develop new, personcentred models for people with a mental illness. FACS supports the Productivity Commission's recommendations for the NDIS, including that it be funded by the Commonwealth Government and that it should meet the disability support needs of people with significant and enduring psychiatric disability who have scope to be supported in the general community. The NDIS can drive better integration of services for people with psychiatric disability, supporting better outcomes.

New models of support for families with complex needs may also be beneficial. Providing holistic support tailored to the needs of all family members will require new approaches and would be supported by improved alignment of mental health services with the range of services supporting these groups.

A key barrier to achieving this service alignment is the differing priorities and thresholds for intervention between different services. Mental health services are provided on the basis of an assessment of the level of mental health need, whilst FACS services will respond to the level of need for each of the FACS service offerings. Individuals may have mental health conditions which significantly contribute to their need for housing or for a child protection intervention for example, however these mental health conditions may not meet thresholds for a specialist mental health service response. Similarly, whilst mental health needs will be considered in prioritisation for FACS services, the severity of a mental health condition will not directly influence the priority given to an individual for a particular service.

Since the amalgamation of previously separate agencies into one FACS, we have worked on better linking what were previously, at best coordinated services for common client groups. This has included negotiating on the alignment of thresholds for specific client cohorts within government policy priorities. This has resulted in for example development of improved links between the disability and public housing services delivered by FACS.

A more integrated and person-centred approach for people with mental health related disability will require consideration of future priorities and consideration of the broader implications of service thresholds on the achievement of government objectives.

<sup>104</sup> NSW Ombudsman, Inquiry into the access of mental health inpatients to accommodation and support services under the Disability Services Act 1993: Draft Report, p.53, July 2012.

### **Appendix 2: Stakeholders consulted**

Organisation	Number of people	Inquiry Reference Group
NSW Ministry of Health, including:  • Mental Health and Drug and Alcohol Programs (MHDAO)  • InforMH  • Southern NSW LHD  • Northern NSW LHD  • South East Sydney LHD  • Hunter New England LHD  • Northern Sydney LHD  • Sydney LHD  • Sydney LHD  • South West Sydney LHD  • Western Sydney LHD  • Illawarra Shoalhaven LHD  • Western NSW LHD	77	A/Prof John Allan, Chief Psychiatrist; and representatives from MHDAO
Ageing, Disability and Home Care (ADHC), including:  Accommodation and Policy Development Directorate  Community Care  Office of the Senior Practitioner  Metro South Region  Metro North Region  Hunter Region  Northern Region  Southern Region	30	Ethel McAlpine, Deputy Director-General
Housing NSW	5	Vivian Hanich, Director, Service Development Strategy
Public Guardian	50	Graeme Smith, Public Guardian; and Frances Rush, Assistant Director, Advocacy and Policy
Mental Health Official Visitors	8	Jan Roberts, Principal Official Visitor; and Elayne Mitchell, Team Leader OV Program
Mental Health Review Tribunal (MHRT)	54	Maria Bisogni, Deputy President, Civil Division; Rodney Brabin, Registrar
Mental Health Coordinating Council (MHCC)	2	Jenna Bateman, CEO
NSW Consumer Advisory Group (NSW CAG) and consumers	18	Dr Peri O'Shea, CEO
A/Professor Julian Trollor, Chair, Intellectual Disability Mental Health UNSW	1	Yes
Mental Health Advocacy Service (MHAS)	4	
ARAFMI and family members	7	
MeNGO mental health organisations, including:  UnitingCare Mental Health Richmond Fellowship Psychiatric Rehabilitation Association  NEAMI New Horizons On Track St Luke's Schizophrenia Fellowship HOME in Queanbeyan Aftercare Association Camperdown Support Services	12	
People with Disability Australia	2	
Matthew Talbot Homeless Persons Service	3	
A/Professor John Basson, UNSW Department of Developmental Disability Neuropsychiatry and Consultant Forensic Psychiatrist in Sydney West LHD	3	
Dr Keith Johnson, UNSW Department of Developmental Disability Neuropsychiatry	2	

### Appendix 3: Mental Health Act 2007

Mentally ill persons and mentally disordered persons are defined in the Act. People can be admitted *voluntarily* to a mental health facility whether or not they are mentally ill or disordered, however *involuntary admission* is only possible if the person is found by an authorised medical officer to be mentally ill or disordered.

The Mental Health Review Tribunal (MHRT) is responsible for undertaking mental health inquiries following the involuntary detention of a person in a mental health facility. A person who is found to be a mentally ill person must be brought before the MHRT 'as soon as practicable'. This usually occurs about three to four weeks after involuntary admission.<sup>105</sup>

A person can be discharged before the inquiry is held if the authorised medical officer agrees they are well enough to be discharged. A detained person, or his or her primary carer, can request that the person be discharged, and can appeal the decision if that request is not met. In such cases, the MHRT must hold an appeal hearing as soon as possible.

To extend a person's involuntary stay beyond the period set by the initial Involuntary Order, the mental health facility must apply to the Tribunal for a further Involuntary Patient Order before the first order expires. If the Tribunal makes a further order, the patient continues to be detained as an involuntary patient until s/he is well and no longer qualifies as a 'mentally ill person'. The patient must be discharged if s/he is found to no longer be a mentally ill person.

The Tribunal must review each involuntary patient at least every three months for the first 12 months the person is an involuntary patient and, thereafter, at least once every six months or, if considered appropriate, at intervals of up to 12 months. Reviews can also occur at any other time as the Tribunal sees fit.

At review, consideration must be given by the Tribunal to the least restrictive environment in which care and treatment can be effectively given. Section 38(4) provides that mentally ill people must be detained if no other suitable accommodation is available:

If the Tribunal determines that the patient is a mentally ill person and that no other care of a less restrictive kind, that is consistent with safe and effective care, is appropriate and reasonably available to the patient, the Tribunal must make an order that the patient continue to be detained as an involuntary patient in a mental health facility for further observation or treatment, or both.

At review, people can be discharged without any further order or with a Community Treatment Order (CTO) made for up to 12 months. CTOs may provide for people to attend treatment, counselling or undertake rehabilitation, be visited at home by community mental health workers, and/or take medication as prescribed.

Voluntary patients can discharge themselves or be discharged by an authorised medical officer or by the MHRT after a review. Reviews of voluntary patients by the MHRT have to occur once every 12 months.

<sup>105</sup> Mental Health Review Tribunal (2010) Hearing Kit, updated June 2010.

# Appendix 4: Access to supported accommodation not covered by ADHC's *Allocation* policy

### **Drop-in support**

There are a number of disability accommodation and support programs that include drop-in support options, including the Community Justice Program and the Disability Housing and Support Initiative. There are specific drop-in support models for people with ABI, for Aboriginal people with disabilities, and for people from CALD communities.

The drop-in support service model provides up to 35 hours of direct support per week, for people with disabilities who require low to moderate levels of accommodation support. Access is via ADHC's regional IRI teams. In 2010/11, 2,368 people accessed in-home accommodation support, typically from ADHC-funded NGOs. Three per cent (71) had a primary psychiatric disability.

### The Disability Housing and Support Initiative (DHASI)

The DHASI program is a partnership between Housing NSW, ADHC, and non-government disability services to assist people with disability to maintain social housing tenancy through the provision of drop-in support. To be eligible, a person must have an intellectual disability or ABI. As at 30 June 2010, the program was at full capacity, supporting 50 people. There are no current plans by ADHC or Housing NSW to extend the program.

### **Community Justice Program (CJP)**

The CJP provides specialised accommodation and pre- and post-release support services to people with intellectual disability exiting custody. Entry to the program is managed by ADHC's Office of the Senior Practitioner, and is contingent upon the person being eligible for ADHC services (that is, they must have an intellectual disability). People with psychiatric disability are eligible only if they also meet the intellectual disability requirement. ST2 includes funding for an extra 200 CJP places over the next five years; to reach 400 places in total.

### Younger Persons in Residential Aged Care Program (YPIRAC)

The YPIRAC program is a joint Commonwealth and NSW Government funded program that aims to provide more appropriate living options and practical support for some younger people with disabilities living in, or at risk of entry to, residential aged care. Eligibility for the program includes having a disability as defined in the DSA, acquired after the age of 18 years, which would include people with psychiatric disability. However, applicants must also be aged below 65 years, and living permanently in residential aged care or at risk of entry into residential aged care. The priority is people younger than 50 years, who are living permanently in residential aged care.

### **Integrated Services Project (ISP)**

The ISP is administered by ADHC in partnership with NSW Health and Housing NSW. It provides intensive support to approximately 24 adult clients a year who have been identified from across the service system as having complex needs and challenging behaviour. The project provides a range of additional time-limited services, including comprehensive assessment, behaviour support,

supervision, case coordination and accommodation. The service model includes a range of accommodation types and flexible support, ranging from drop-in support to 24-hour on-site support.

The ISP has been evaluated as a successful model of accommodation and support, with a range of positive outcomes for clients, including reduced frequency and severity of challenging behaviour; and decreased hospital admissions and lengths of stay.<sup>106</sup> It is currently only available in metropolitan Sydney.

To be eligible for the ISP, a person must:

- exhibit behaviour that places themselves and/or others at risk of harm;
- either have one or more disability or diagnosis, or have a diagnosis that is in dispute;
- require a high level of coordinated multiple agency response;
- live in insecure accommodation;
- have significantly impaired access to essential services due to their behaviour; and
- have exhausted all other options for support.

<sup>106</sup> UNSW Social Policy Research Centre (2010) Evaluation of the Integrated Services Project for Clients with Challenging Behaviour, final report.

# Appendix 5: Community accommodation support models in Australia

### Step-up and step-down accommodation

Except NSW, all jurisdictions in Australia have a specific program that provides step-up/ step-down services, run by NGOs. These services provide intensive, short-term support for people leaving acute care who are not yet able to return to their previous setting (step-down), and to people living in the community experiencing increased symptoms or stresses who need additional support to prevent acute admission to hospital (step-up). One example of this model is the Prevention and Recovery Care (PARC) services in Victoria, in which support is provided for up to 28 days by NGOs (accommodation support) and mental health services (clinical support).

### Other transitional accommodation support

Similar to NSW, some other states in Australia have government and/or NGO operated transitional accommodation support. As is the case in NSW, the government-operated services have clinical mental health staff, and the NGO services have non-clinical staff.

The health departments in Victoria, Queensland, and South Australia operate community-based transitional residential services that have a clinical rehabilitation focus, staffed on a 24/7 basis by mental health nurses or other clinical staff. The support tends to be provided in cluster accommodation arrangements for periods of up to two years. Victoria and Tasmania have NGO-operated transitional rehabilitation residential services, with non-clinical staffing, for up to three years. Some of these provide 24/7 support.

### **Supported accommodation**

In Australia, various supported housing models exist. All jurisdictions operate supported accommodation services that have similarities to HASI in NSW, typically known as Housing and Support Programs (HASP). Most HASP services require individuals to have independent living skills sufficient to manage with drop-in support, and are premised on single-occupancy accommodation. HASP services typically provide a lower amount of support than is currently available under HASI – up to around 30 hours per week. However, as part of a reform program underway in South Australia, a cluster of 20 units under HASP will provide 24/7 support.

### **Project 300 and HASP**

Supported housing models in Queensland include HASP and Project 300, both of which are funded and managed by the state disability agency, and have been evaluated as successful models. Project 300 commenced in 1996 to assist up to 300 people with severe mental illness and associated disability to transition from three psychiatric hospitals to the community. HASP was established in 2006 to support people with psychiatric disability leaving acute and extended treatment mental health facilities who had been unable to be discharged due to homelessness or risk of homelessness.

Both programs are similar to HASI in NSW, involving partnership arrangements between housing services (accommodation), mental health services (clinical support), and NGOs funded by the government disability agency (disability support). Neither model provides 24/7 support – the non-clinical support allocated to each person in Project 300 started at 53 hours per week, but has ranged up to 109 hours per week; and non-clinical support under HASP starts at an average of 27 hours per week.

### **Supported Accommodation Services**

In Victoria, NGOs operate Supported Accommodation Services, which provide long-term stable and 'home like' accommodation for people with marked psychiatric disability resulting from severe mental illness, and who require a structured, supportive environment. Residents are able to stay as long as they like, and typically have tenancy rights. Accommodation includes flats or bed-sits in one large dwelling, or a cluster of units on the one site. Non-clinical staff provide disability support, which may be based on-site or provided on an in-reach basis according to residents' needs. Some of the beds are staffed on a 24/7 basis.

### **Housing First and Common Ground**

Some jurisdictions, including NSW, have started to introduce other models of supported housing, some of which are based on the 'Housing First' approach. Developed in New York in 1992, Housing First is an approach to the provision of permanent supported accommodation for homeless people, including people with mental illness and/or substance dependency issues. Key features of this model include that:

- the only condition of housing is payment of rent (30% of income) and compliance with a tenancy agreement;
- there is choice about the nature and extent of engagement with support services beyond participating in two home visits per month with the case manager;
- Assertive Community Treatment is available 24/7;
- support services can reduce or increase as needed, and are available long-term; and
- housing is scattered in the community, and if a block of units is used by the program, then only 15 to 20 per cent are rented by Housing First clients.

Versions of Housing First are being rolled out in NSW, SA, Victoria, and the ACT, linked to national plans to address homelessness. The Common Ground model in Sydney opened in November 2011, and comprises a block of 104 one and two-bedroom units. Half of the units are allocated to chronically homeless people, and half provide affordable housing for low income workers and social housing.

Support services operate on-site between 8am and 6pm, seven days a week. A community housing organisation manages the tenancies, and has subcontracted five NGOs to jointly staff Camperdown Support Services to provide the support.

### **HOME** in Queanbeyan

In 2010, a new model of supported housing opened in NSW. HOME in Queanbeyan provides accommodation and 24-hour support to people with chronic mental illness, comprising 20 one-bedroom units, with 15 places for long-term residents and five respite places. All of the ongoing residents receive on-site pastoral care and support; clinical case management from the community mental health team; and some are linked in with Personal Helpers and Mentors services, TAFE, or employment.

The model does not include recurrent government funding. Capital works were funded via federal and state governments and significant fundraising, and ongoing costs are currently funded by a charitable foundation and through community fundraising.

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