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[1] 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[2] that was likely to be permanent;

1 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.

2 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.