Paving the way home

Lessons from *My Choice: Pathways to Community Living Initiative*

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SPOTLIGHT ON REFORM
A South Western Sydney Local Health District craft project; where Pathways To Community Living consumers made coasters with a statement about their aspiration for their future home. These have been widely distributed within services as a way of keeping the consumer voice at the forefront of our thoughts.’ Clinician, Local Health District

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Staff from Macquarie Hospital at the PCLI Dialogue Day, May 2018, one of the many hospital sites involved in this program
1. Foreword

A hospital is not a home. We all know, from our own stays in hospital or from visiting loved ones, that even the best inpatient care does not rival the comfort and safety we feel when we are in a space of our own, with the people, animals and belongings we love. As one person who lives with mental health issues puts it so perfectly in the artwork featured throughout this document: “My home is everything”.

The NSW Government recognises the vital role that home plays in recovery and healing from mental health issues. In 2014, it began a program to support people with enduring and serious mental health issues who have been in hospital for long periods to move into suitable community care. Called the Pathways to Community Living Initiative (PCLI), the program is being led by the NSW Ministry of Health and is the focus of this report.

The PCLI is a direct response to the call in Living Well: A Strategic Plan for Mental Health in NSW 2014-2024 to increase the availability of community mental health services and supports in NSW, and provide community-based alternatives to long-stay hospital care.

In the past, there has been an over reliance on hospitals in NSW to provide mental health care. People needing high levels of clinical care have been at risk of remaining in hospital for extended stays, because of inadequate services in the community to support their recovery.

There will always be people who need a significant level of mental health care or support. Some people will need 24 hour care. Finding this care outside of hospital is a basic human right.

The PCLI rises to this challenge. At the program’s beginning, the NSW Ministry of Health identified 380 people across the state with mental health issues who had been in hospital for more than 12 months. The first stage of the PCLI has focused on developing accommodation for the people in this group who live with both mental health and ageing related issues. Some of them have been in hospital for more than 20 years.

By December 2017, more than 360 people had participated in assessments to determine their needs and wishes, and around 100 people from the original group identified as long-stay patients had moved out of hospital, including 40 people with ageing related issues.

NSW Government investment has made this happen. We know that lasting reform takes time, and requires a number of approaches and efforts to support it. The PCLI is an example of this and I look forward to its comprehensive approach to supporting people’s needs, strengths and wishes becoming business-as-usual across mental health services.

To help make this happen, the NSW Mental Health Commission has charted in this report the strategies that have been used in the first years of the PCLI to achieve reform: new partnerships, culture change, distributive leadership, clear communication strategies and open dialogue. We have drawn on the perspectives of people with a lived experience of mental health issues, families and carers, and people who work within the mental health system and partnered aged care services.

I express my gratitude to the NSW Ministry of Health and Local Health Districts, aged care providers and to people with a lived experience of mental health issues and families and carers who shared their experiences with us. I also express my thanks to the staff who have cared for their patients and supported them in a move of their choice.

We look forward to hearing more of these positive stories as the Initiative continues. By sharing elements of good change management in NSW, we can create a collaborative movement to drive reform within our services. I urge others to learn from these strategies.

Catherine Lourey
NSW Mental Health Commissioner
2. A note on language

The Commission recognises that words and language can have a profound impact on people. The use of inclusive and contemporary language empowers people and allows important issues to be aired with sensitivity while minimising stigma.

The Commission also recognises that words and terms are sometimes contested and are subject to change for appropriateness in various settings. The language used to describe lived experience in particular is still evolving.

This report on the Pathways to Community Living Initiative focuses on a small group of people who have been in hospital in NSW for 12 months or more and need a high level of support for their recovery journey. Sometimes this includes needing 24-hour care in the community, which has prevented them from being discharged from a hospital setting in the past. For this reason, in this publication we have used the term ‘long-stay patient’ to describe this group of individuals, instead of other language such as ‘clients’, ‘consumers’ or ‘people experiencing extended care in hospital’ although we acknowledge all are interchangeable.

Aged care
A general term referring to the range of residential care and community support services provided to people with issues related to ageing.

Carer
Carers are people who care for, support or are a family member or friend of someone with mental health issues.

Clinician
A health professional such as a general practitioner (GP), psychiatrist, psychologist, nurse, or occupational therapist who is directly involved in patient care.

Community care
Non-hospital based mental health care outside of a hospital. In the context of this report this can mean 24-hour care in a community-based facility, or aged care unit, as well as other supports in the community such as mental health teams.

Lived experience
For the purposes of this report, people who have experienced a mental health issue and have recovered, or who currently have mental health issues and are on their recovery journey are described as having ‘lived experience’. We also acknowledge that some people use the term ‘lived experience’ to describe the experience of caring for or supporting someone with mental health issues.

Long-stay patient
People who have been in hospital receiving mental health care in NSW, for 12 months or more.

We acknowledge that other terms such as ‘clients’, ‘consumers’ or ‘people who have been in hospital experiencing extended stays’ are preferred by some.

Pathways To Community Living (PCLI)
The Pathways To Community Living Initiative is a program that focuses on finding alternative accommodation for around 380 people in NSW with severe and persistent mental illness who have been an inpatient in a mental health facility for 12 months or more.

Mental Health Aged Care Partnership Initiative (MHACPI)
In the context of the PCLI, the Mental Health Aged Care Partnership Initiative is a partnership between a health service and an aged care provider where specialist care is provided in the community to people with issues of ageing and mental illness. The term ‘MHACPI Unit’ refers to a specialist, purpose designed aged care unit, set up to meet the support needs of long-stay mental health patients. These units are also referred to as ‘specialist aged care mental health units’, ‘specialist units’ or ‘high care units’ by the staff working in them.

Recovery
The ability to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues.
A key recommendation in *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024* is to improve community-based mental health care in NSW. Historically, NSW has been overly reliant on hospitals in the delivery of mental health care. This meant that people who were experiencing a significant mental health crisis who needed a range of clinical supports in NSW were likely to use hospital services in the absence of suitable community-based alternatives. People who have been admitted to mental health inpatient facilities have often stayed too long, and become ‘lost’ in the mental health system after leaving hospital, because of inadequate follow up.

Despite policies and research long recognising the detrimental effects of institutionalisation, it was still common practice in NSW at the time of *Living Well’s* publication in 2014 for people to stay in hospital long after they needed to. Around 50 per cent of non-acute beds and three per cent of acute beds had accommodated people in hospital for more than one year, with the number of people staying in hospital for longer than 12 months in NSW at around 380 each year. Most of these people were accommodated in stand-alone psychiatric hospitals which have been targeted for closure since the 1980s through various policies aimed at ending NSW’s reliance on institutional psychiatric care. These hospitals are currently under the governance of Local Health Districts.

Australia is not alone in its over reliance on inpatient mental health care. Globally, inpatient hospital care still dominates mental health service delivery and investment, and people experiencing mental illness remain at risk of staying in hospital for long-term stays due to a lack of community-based support. Changing this trend requires government investment and a concerted effort by policy makers. It also requires providers who are willing to increase the availability of clinical community-based support (in particular for those who need 24-hour care), changes in professional practice and most importantly, collaboration between all services, people with a lived experience of mental health issues, their families and staff. The Italian region of Trieste is an example of positive reform in this area. The Trieste psychiatric asylum once accommodated more than 1,200 people but now 94 per cent of mental health funding supports access to 24-hour clinical community care, seven days a week.

Significant and long lasting reform that reduces the reliance on hospital beds takes time.

The *My Choice: Pathways to Community Living Initiative* (PCLI) is a key component of the NSW Government’s Mental Health Reform 2014-2024 package, announced in December 2014, as part of the response to *Living Well*. Led by the NSW Ministry of Health, the Initiative aims to support people with enduring and serious mental illness across NSW who have been in hospital for more than twelve months to, wherever possible, move out of hospital into suitable community care. Commencing operations in July 2015, the PCLI sees Local Health Districts, community support agencies and people with mental health issues and their families and carers working together to achieve a successful transition that is informed at all times by the strengths, needs and wishes of the individuals receiving care while maintaining their clinical support. By December 2017, more than 360 people had participated in comprehensive assessments to determine their needs and wishes.

The PCLI service development model is being rolled out over two stages based on the care needs of different groups of long-stay patients. The first stage, which began in 2015, focuses on the needs of around 100 people with ageing related issues. With investment by the NSW Government, the NSW Ministry of Health and Local Health Districts have been working with aged care providers to determine the best way to safely transition each person in long-stay hospital care into a community setting, based on their individual strengths, needs and wishes. This stage has included the development of three Mental Health Aged Care Partnership Initiative...
(MHACPI) transition units within residential aged care facilities, two specialist residential aged care facilities, and partnerships with generalist residential aged care providers. By December 2017, over 40 per cent of the initial 100 people experiencing ageing related issues had successfully transitioned to community-based care.

The second group of people that the Initiative will assist is around 280 younger people, aged 18 years and upwards with high clinical needs. Additional planning and investment by the NSW Government, the NSW Ministry of Health and Local Health Districts is required to ensure suitable community-based accommodation and supports are available for these individuals. To achieve this, new innovative models of care are being designed. To support this next stage of service development, the Minister of Health recently committed up to 260 step-up step-down community-based beds in the budget announcement for 2018-19.

This report highlights some of the successes, challenges, and changes of practice that have characterised the first years of this important Initiative. While it is early days to demonstrate the long term outcomes of the PCLI, the anecdotal reports and approaches outlined in this document provide enormous hope that the PCLI will achieve significant benefits for everyone involved and cement a new way of working for the future.

Resident going for a walk with an aged care worker, Mission Australia, Annie Green Court, Redfern
4. Building the foundations of the PCLI

“PCLI recognises a person’s right to the best care in the least restrictive environment. Hospital treatment should be when people require intensive care, not the only option. Hospital is a place for specialist and acute care. Most of our healing occurs in the community surrounded by friends, family, and nature.” Peer worker, Local Health District

4.1 Principles for success

After a report by the NSW Ombudsman in 2012, staff from Kenmore Hospital in Goulburn, NSW, responded to the Ombudsman’s recommendations to reduce the number of long-stay mental health patients in their inpatient services\(^6\). At Kenmore a small group of dedicated nurses, a consumer advocate and executives from the Local Health District came together and identified barriers to discharge from hospital for a group of older patients who had been in hospital for 12 months or more. Over two years they were successful in finding placements for 19 older patients with issues of ageing in alternative accommodation and aged care services. This became a precursor to the PCLI and a great example of the power of persistence and local leadership.

In anticipation of Living Well’s adoption by Government in December 2014, a number of senior executives from the NSW Ministry of Health visited facilities across NSW between June and December 2014 to look at what support was required to move long-stay patients to the community\(^7\). Findings were similar to those in international studies, meaning that a new, multi-faceted approach was needed that would reduce the reliance on hospital beds in NSW, and create a culture within NSW mental health facilities that honours and advocates for every person’s right to live in the community.

It would no longer be acceptable for a person to stay in hospital longer than they needed.

Removing the reliance on hospital beds and building up community options has been a global issue in mental health reform that is not unique to NSW or Australia. In 2014, the World Health Organisation (WHO) undertook an expert survey to look at the most successful methods to reduce the reliance on inpatient beds\(^8\). Seventy-eight mental health experts from 42 countries participated and were asked to rank how useful they found different methods to reduce institution-based services.

The most useful methods were as follows:

- mobile clinics and outreach services (67 per cent)
- psychiatric beds outside mental health hospitals (64 per cent)
- discharge planning and hospital to community residence transfer programs (58 per cent)
- residential care in the community (57 per cent)
- stopping new admissions in institutions or “closing the front door” (56 per cent).

Experts identified that regardless of country or culture, there needed to be more than new services to ensure the successful reduction of institution-based care. Other necessary actions included rallying support, aligning finances, and capitalising on timing. These are summarised in five key principles for success on page 9.

The PCLI team harnessed these principles to begin the roll out of the project across NSW. The name for the initiative was proposed by a family member of a person who had been in hospital for many years. From the start, PCLI had political support from the highest levels of Government, including the NSW Minister for Mental Health, as well as the backing of senior executives within the NSW Ministry of Health and key psychiatrists who would champion change within their services. This commitment was made watertight with a $115 million investment by the NSW Government towards overall mental health reform and the approval of a detailed business case by Cabinet in September 2015\(^9\).

“It was very clear from the beginning that the PCLI was more than a funding pool available – it was to become a new way of working.” Executive, Local Health District

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PRINCIPLES FOR SUCCESS

Community-based services must be in place

Through the reallocation of resources, community-based services must be in place (prior to reducing the reliance on inpatient beds) which are inclusive of evidence-based clinical care and access to social services, housing, employment and community participation.

The health workforce must be committed to change

Changing ways of working and the commitment of the health workforce to reducing the reliance on long-term beds is key, taking into account the skill, knowledge and care planning that experienced staff can bring to working with long-term residents. While staff may have valuable views that should be harnessed they also may have concerns about losing employment, familiar ways of working or learning new skills.

Political support at the highest and broadest level is crucial

Support across a broad group of stakeholders can help gather momentum for change and overcome resistance. Groups that need to be supportive include service users and their families, academic leaders, politicians, health professionals and the wider community.

Timing is key

Moments of openness such as changes in health or political leadership can provide the right opportunity to introduce changes and reform. While success is not assured in taking this approach, the experts noted that skill is required to recognise and act on these moments when appropriate.

Additional financial resources are needed

A key and final principle noted by the experts was that the reduction of beds should not be a cost-saving exercise and that delivering community-based, population-wide services can be more expensive than hospital care. Reform and changes in service provision will also incur up-front costs and there may be a period of double funding, such as for the training of staff or establishing new community-based services.
4.2 The PCLI target population

"It’s not that people are not receiving the best treatment and care already. But spending your life in a hospital setting is just not normal." Sandra Morgan, Consumer Advocate

In light of the NSW Government’s adoption of Living Well, the accompanying funding boost for mental health reform and the coming of the National Disability Insurance Scheme (NDIS), work could start on helping people move to a different model of support when they were ready to do so.

At June 2014:

- 336 clients were accommodated in six major mental health hospital sites in NSW: Cumberland, Macquarie, Morisset, Liverpool, Kenmore, Bloomfield (Orange) and Concord
- 44 clients were located in other NSW sites.

Initial assessments with individuals revealed their care needs were greater than what could be provided by existing services such as the NSW Housing and Accommodation Support Initiative (HASI). HASI provides packages of care to mental health clients living in public housing or supported accommodation, but is not designed for people with very complex needs. The NDIS did not necessarily provide a solution as it is only available to people aged under 65 years. Assessments revealed people eligible for the PCLI program had needs such as requiring up to 24-hour support to undertake daily living activities; safely express their needs; access the community; maintain relationships; and ensure their safety from harm or neglect. New models of care needed to be created and adequately funded to meet these needs.

The PCLI advocates that there is no ‘one size fits all’ approach to moving people back into the community, but a unique journey and plan for each individual, detailing their own and their families’ wishes, strengths and vulnerabilities, support requirements and the time they need to transition safely.

"There are some people who may always need the support of a psychiatrist…. they do have a level of [mental] illness and they may relapse. But they can always come back to our unit [and] be re-assessed if the person does get ill again." Manager, Local Health District

For some people who had been in hospital for many years and were eligible for the PCLI, the start of the program meant re-imagining what their future would look like. After so many years in inpatient care, many PCLI clients, their families, and indeed even staff, had come to regard the hospital ward as their home. Many people were there because they had run out of options, having been labelled as “too complex” and with previous attempts to find alternative accommodation or trial community services been undertaken without success. There were many legitimate concerns from families and staff around the possibility of things ‘going wrong’ as people moved back into the community, and fears services outside of the hospital would not be able to meet their multiple clinical needs. For example, some families were concerned their older relatives who were eligible for the PCLI stood to lose a stable, familiar environment where they had their symptoms under control, only to be moved to an aged care service that may not be able to adequately support them.

"There was a feeling from the [inpatient] staff that they had looked after these clients for years and years and how could anyone else manage to do that?" Manager, Local Health District

The work that lay ahead for the Local Health Districts and for the NSW Ministry of Health leading the project was more than just finding housing solutions. Discussions with clients and families about transitioning to life outside of the hospital needed to be both sensitive and timely. Staff had to learn new assessment tools, challenge long-held assumptions, and discover new ways of working with clients they had known for many years. Everyone’s fears and risks needed to be negotiated slowly and supportively. But with political support, the backing of senior executives, additional funding and new partnerships, there was no doubt that change was going to happen.

"Changing culture can take quite a while. People had seen what they were doing as good and meaningful, and to think that is not best practice anymore is confronting." Executive, Local Health District
The next sections of this report focus on the experiences of one Local Health District and one aged care provider who formed a partnership in the first years of the Initiative, and set up a MHACPI unit within a community residential aged care setting. This is one of three specialist aged care units across NSW which were set up to specifically accommodate PCLI clients with ageing related issues. They are based on an evaluated model of two previous such units in metropolitan Sydney.

4.3 Communication paves the way

When the project to move long-stay patients was included as part of the Mental Health Reform package announced to the public in December 2014 by the Government and the NSW Ministry of Health, the community understood why long-term care was shifting to a community-based model. A statewide communications plan explained clearly the reasons why these moves needed to be made and predicted questions that people in hospital and their families, staff and the community would have.

For staff and key stakeholders this communications strategy with clear messaging was required to ensure the project gained early support and addressed everyone’s questions and concerns. Failure to do so could raise unnecessary alarm, spread angst among people with a lived experience of mental health issues, their families, carers and staff, and create distrust and a negative perception of the Initiative.

Questions from people with lived experience of mental health issues, the public, staff and families were workshopped during the project planning phase and answers were developed into accessible, publicly available fact sheets (available on the NSW Health website).

Questions from stakeholders included:

“Does this mean mental health hospitals are closing?”

“Are families expected to provide care for their loved ones?”

“Will I lose my job if the number of patients in hospital reduces?”

Answers to these questions and other messages were included in the state-wide communication plan that was provided to all Local Health Districts in 2015. There was no room for misinterpretation, or mixed messages about the intention of the PCLI, which has the best interests and the rights of people with a mental health issues at its core. Local Health Districts could use the communication plan and adapt accordingly, but there was to be no deviation from the key messages below.

Key messages:

“This is not the closure of mental health units”

“People requiring hospital care will always be able to receive it”

“Everyone has the right to live in a community setting”

“Evidence shows that good quality community-based care can reduce the need for hospitalisation”

“Each person will move only when it is right with them”

“Transition to community living will be tailored to individual needs with supported housing, clinical care and a gradual transition to the community”

“As community-based models of care are enhanced there may be changes to staff requirements. Affected staff and unions will be consulted prior to any changes.”
“It was clear when it was announced the project had been well thought out, researched and funded.” Executive, Aged Care Service

Information about the implementation of the PCLI and people’s individual responsibilities was delivered within Local Health Districts through a range of methods suited to each audience, including but not limited to:

- informal meetings
- focused conversations
- fact sheets
- forums
- workshops
- media releases
- videos.

These methods were used on their own or together depending on the level of engagement or outcome required.

Among the audiences that needed clear communications at the beginning of the project were the residents of the aged care specialist unit that was due to accept some of the initial PCLI clients. Although the service already had residents who had mental health issues, any stigmatising attitudes about those being transferred from long-stay psychiatric inpatient units to the aged care service’s high care unit – such as, that they were violent – needed to be broken down and countered with accurate information. This was done by communicating simple messages, including explaining that there was no difference between the residents, just that some individuals were in a different phase of their recovery journey, as well as allowing the clients from the high care unit and the mainstream unit to interact where possible.

“We now take some of the specialist unit residents out to lunch with the mainstream residents.” Manager, Aged Care Unit

The table on page 13, adapted from the International Association for Public Participation, gives an overview of the PCLI project team’s approach to informing and consulting with stakeholders who were affected by the Initiative.

PCLI fact sheets and associated media used to support some of this consultation are available on the NSW Health website.

Among the communication methods employed by the PCLI team are Dialogue Days, which draw on the principles of Open Dialogue, a mental health treatment approach originating from Finland in the 1980s. When used in a clinical setting, Open Dialogue sees the person with a lived experience of a mental health issues brought together with their family, friends and supporters, clinicians and other health professionals to explore perspectives on their illness and possible interventions in an open way. The aim of the approach is not to reach a rapid solution, or make quick and fast changes. It is to fully explore and understand the issue being presented, and the impact it will have for the person with mental health issues and their family.

In the PCLI project, Dialogue Days are held three or four times a year to bring clinicians, project planners and people with a lived experience of mental health issues together to discuss thoughts, case studies, and approaches for the Initiative. By using these events in the project’s planning, delivery and monitoring, the PCLI team have harnessed a culture of collective leadership and shared learning. Since 2015, a number of Local Health Districts across NSW have used the methodology to work through local issues around the Initiative’s roll out, to seek innovative solutions from participants, and most importantly to share successes. Dialogue Days support the distributive leadership approach for the PCLI, where expertise is not assumed but instead shared responsibility is promoted, to help ensure success and lasting change.
### Overview of approach to informing and consulting with stakeholders

<table>
<thead>
<tr>
<th>Action</th>
<th>Public participation goal</th>
<th>Who?</th>
<th>Example techniques</th>
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| Inform | To provide the public with balanced information to assist them to understand the issue, alternatives, opportunities and solutions | - General public  
- Staff unions | - Fact sheets  
- Videos  
- Media releases |
| Consult | To obtain feedback on analysis, alternatives and decisions | - Local Health District  
- Peak mental health and carer bodies  
- Relevant government agencies  
- People with a lived experience of mental health issues, families and carers | - Focus groups  
- Forums  
- Focused conversations |
| Involve | To work directly with the public throughout the process to ensure that concerns are consistently understood | - Mental health directors  
- Mental health executive  
- Clinicians, managers and consumer consultants  
- People with a lived experience of mental health issues, families and carers | - Workshops |
| Collaborate | To partner with the public in each aspect of the decision including the development of alternatives and preferred solution. | - Public Guardian  
- Mental Health Review Tribunal  
- Aged Care and community-managed services  
- Local Health District executives  
- People with a lived experience of mental health issues, families and carers | - Dialogue Days  
- Workshops |
| Empower | To place final decision making in the hands of the person | - People with a lived experience of mental health issues, families and carers | - Conversations  
- Informal meetings  
- Delegated decision making |
5.1 Leadership, culture change and learning along the way

While the NSW Ministry of Health has provided high-level leadership and governance for the PCLI across NSW, its local implementation has been achieved via the collective effort and distributed responsibility of project managers, mental health executives and clinicians. Leadership at a local level is key.

Collective leadership means:

“the distribution and allocation of leadership power to wherever expertise, capability and motivation sits within an organisations.”13

“The purposeful, visible distribution of leadership responsibility onto the shoulders of every person in the organisation is vital for creating the type of collective leadership that will nurture the right culture for health care.”14

The first step for these staff in rolling out the PCLI within their Local Health Districts was to shift a number of practices and attitudes among their colleagues and clients. In some hospital sites each ward had their own separate way of working including patient entry and exit criteria, and visiting arrangements for families. Staff were protective of people who had stayed in the wards for a long time. In some cases, people receiving care regarded hospital staff as the most significant and trusted people in their life and there was a risk they would feel abandoned when the idea of new living arrangements was introduced. It was important that the opportunity to transition was framed in a positive light, from the people they trusted the most.

“For some people the concept of having a home that wasn’t the hospital was non-existent.” Clinician, Inpatient Unit

To achieve this, services began using new language. Wards were no longer seen as ‘home’ but would be talked about as ‘transitional’ to patients, families and staff. Senior clinicians and psychiatrists began to ‘walk the talk’ about the PCLI, championing the change within long-stay wards and promoting the project through formal and informal conversations.

“Somehow the message that the [inpatient] unit was transitional had been lost over time. I started having different conversations earlier… using language like ‘the acute care is now complete and now we should look for new options.’” Clinician, Inpatient Unit

Along with the roll-out of the communication tools outlined above, a flexible assessment process known as ‘Getting to Know You’ was developed to create individual transition plans. This process was developed by a state wide Assessment Task Group made up of senior clinicians, Local Health District and consumer representatives and signified a new way of working to plan the journey home.

Clinicians were provided with training to use the ‘Getting To Know You’ tools and were encouraged to ‘go back to the beginning’ with patients who they might have known for many years.

“We had to assess our own capabilities and look at what tools we were using, what are our capabilities to do the new assessments and what training did we need?” Executive, Local Health District

The PCLI assessment process begins with a conversation between the person receiving care, their support people and the clinician, in which the client is encouraged to think about what the word ‘home’ means to them. This can be explored by any creative means, such as drawing or sculpture, and over a number of sessions. The goal is to move people towards imagining an alternative future and is based on the principle that everyone has the right to exercise their capacity and autonomy.
Those leading the assessments ask questions such as

- What reminds you of ‘home’?
- Does this vision include you having pets?
- Are you thinking of any particular location?

This approach sits outside traditional assessments about mental state or the ability to undertake daily living activities and is based on a principle of co-design using a strengths-based approach.

“The Getting to Know You process is about finding out about people and getting a profile of what we know and don’t know. People have enjoyed the process.”

Executive, Local Health District

Facilities with people eligible to take part in the PCLI were given timeframes to achieve assessment Key Performance Indicators (KPIs) and training was provided to staff who were completing the assessments.

“Some staff have a renewed lease of life about their careers and feel they are doing something great. That is the biggest thing.”

Manager, Local Health District

Although teams were given a package of new assessment tools, training and communication aids as described above, the assessment process was a different journey for each individual. ‘The person process’ recognises that transitions out of hospital for PCLI clients are not linear. People with mental health issues and their families and carers may go back and forward a few times in their minds about if and how a transition out of long-stay wards is the right thing for them. But planting the idea for the possibility of life outside the hospital ward was important to getting the process started. Also key was growing everyone’s understanding that the risks involved in moving to a new home could be anticipated and managed. Staff and families’ acceptance of risk was a true sign of progress compared to earlier times when people had forgotten that taking supported risks is an important part of a recovery journey.

“You look for the risks but you have to manage them. You can’t let the risks defeat you.”

Manager, Local Health District

For some clients, the identified risks meant it was not the right time for them to transition to a new living arrangement in the community. However for others, a conversation about why previous attempts to leave hospital were not successful with them and their families was a way to identify barriers to transitioning that might be removable. Assessment teams asked questions such as:

- What went wrong?
- Where and when did it go wrong?
• Why was discharge unsuccessful?
• What are the current barriers to transition?

Barriers that were identified and managed during assessments included risks to personal safety or wellbeing, such as self-harm or harmful consumption of drugs or alcohol; any barriers to maintaining effective medication and treatment plans; vulnerability to being taken advantage of by other people; and for some, the risk of harming others. If they need to, people may return to hospital for a period after transition. Importantly, this does not mean they have failed. It might mean they need a longer transition period, a short stay in hospital to have current treatment plans reviewed, or a new pathway.

For management, the process also created an opportunity to work with staff who were underperforming or not on board with the recovery model.

“In the past our unit was seen as the end of the line for people but the PCLI has enabled our staff to become much more recovery focused. We are not leaving the staff who are not on board with the project to just sit there.” Manager, Local Health District

“Staff have enjoyed the process. It has given people new skills and a new way of working.” Manager, Local Health District

Once a transition plan was identified in collaboration with the person receiving care and their family and supporters, this was complemented with goal setting and a gradual increase of community activities. In the final phase of the assessment, routine tools were used to build a picture of the person’s current mental health and functioning, to aid the community-based provider that would be supporting the person under the new arrangements.

For the staff working in the aged care unit (MHACPI) which would accept a number of long-stay clients, the Initiative also meant a change in practice, significant training and new leadership. Staff were given a choice if they wanted to work in the MHACPI unit, or mainstream aged care, or both. For those who chose to move into the new unit, they were supported with close to 100 hours of training to gain confidence and skills to support this new group of clients.

“There was a lot of questions about how it would work. We had to really support staff through the change.” Manager, Aged Care Unit

“We took the staff into the (inpatient unit) so that they could meet some of the clients we were going to work with. They moved from apprehension to knowing that it was going to be okay.” Manger, Aged Care Unit

Offering choice, without pressure and flexibility, allowed staff to choose if they would like to work in the new unit.

“Some people said yes. Some people said no. But the overall skill and staff competency has risen in our service quite dramatically.” Executive, Aged Care Service
From Kenmore Hospital to the PCLI – A consumer advocate’s view:

Sandra Morgan is a consumer advocate and the state consumer lead for the PCLI.

“At Kenmore Hospital, I was involved in the transition of 19 people who had been experiencing extended care in hospital. I had been visiting the unit for quite a while as an advocate. Every time I would go there, the people would ask me “when can I go home” or “why can’t I go home?” We had what was called a patient-centered care committee meeting, and I took this issue to the meeting. Coincidently, the NSW Ombudsman’s report ‘Denial of Rights: the need to improve accommodation and support for people with psychiatric disability’ was out at the same time. Others had been asking the same questions that I was asking for years. When I put it to the committee, the timing was right to make change possible.

The patient centered care committee commissioned a working party to work through the barriers for discharging people who had been in hospital for extended stays. It consisted of me, the nurse manager, the nurse unit manager, the clinical nurse consultant, the older people’s clinical leader and a discharge planner. The project was overseen and supported by the treating psychiatrist and the executive. At the start we met every week, and then monthly. We identified the people that could transition that had been there for a long time and identified the barriers one by one. Some of the people had been geographically isolated from their homes for decades and others had families still very involved.

Over three years we transitioned 19 people to the community. Today that unit has been reduced from 32 beds to 16 beds and the average length of stay six months ago was around 37 days. One person we transitioned was there just short of fifty years. The PCLI has enabled this process to happen all over the state. People have been exposed to the idea that they are going “home” for the first time. For some people this is home, or in the case of Kenmore, it is normalised aged care. The first thing is introducing the idea that they can leave hospital, and finding out what they would like and working out with their families what their wishes are and what treatment they need.

I think this reform will succeed because the time and effort has been put in to make sure that services in the community meet individual needs and wishes. There is still access to acute care when people need it. The guidelines for assessments are all about the individual person. This ensures that the person and their family is always at the centre of any planning. The community and staff who have cared for them and the staff who will be supporting them once they move are also considered and are an important part of this process. Everyone who embraces this reform needs to be supported including the carers and the staff. They do have some degree of fear as to how their loved one will manage out of hospital. Will they cope? Will they be safe? Consumers, carers, staff and the community all need to be supported through this process and that is what is happening on the ground.”
5.2 Partnerships and trust – to get everyone on the journey

Fusing solid partnerships and creating new referral pathways between aged care services, Local Health Districts and other agencies was critical to the transitions achieved to date for long-stay patients with ageing related issues.

“There was a lot of fear that an aged care unit would not be able to look after our clients. There had to be trust.” Executive, Local Health District

In creating a partnership between the aged care service and the Local Health District, barriers were broken down through the mutual drafting of a memorandum of understanding (MoU), visits to each other’s services and meetings between clinicians to reach common ground. Rather than senior management drafting the MoU, it was reached through a collaborative effort and face to face meetings with a mixed level group of clinicians and executives. This was essential to achieving an understanding of each other’s services, exploring concerns and translating each other’s languages. After a series of meetings, it became clear to participants that although the approach taken by each service was different, everyone shared the same values and wanted the best outcome for the clients and families involved.

“I was looking at this with my mental health hat on and they were looking at it with their aged care hats on. But by the time the meeting was over everyone’s shoulders were relaxed. We could talk through anything that was a concern.” Executive, Local Health District

“There was a difference in the language used between mental health and aged care. At the end of the day, we are all caring for people, we just talked about it in different ways.” Manager, Aged Care Unit

The MoU process demonstrated that creating a shared vision of success between everyone involved is key to managing partnerships effectively. This aligns to the principles of working within a mental health recovery model, where clinicians and clients co-design a vision of recovery and plan how it will be achieved together.

“Leaders need to relinquish some of their expert status and work with individuals in a coaching and collaborative style...both the recovery philosophy and engaging leadership require that we communicate positive expectations of what is possible.”

Just as critical as building trust and partnerships between services was gaining the trust of families. This was not easy. Families had witnessed their loved one move from service to service for many years and understandably were reluctant for the person they cared for to be moved again. Gaining and maintaining this trust will continue to be a challenge throughout the future years of this Initiative.

Another barrier expressed by families of older people in the first years of the PCLI was a financial one. This barrier is one which continues to be addressed. Families did not have to pay for their loved one to receive inpatient care in a public hospital, but a move to a community or aged care service requires a co-contribution based on the individual’s current income and assets.

“They …[families]… have been allowed to think that they get a high level of care in hospital, with no extra payment. This is a new [aged care community] unit, will it work?” Executive, Local Health District

“We have had some families say no. They don’t want the person to move.” Manager, Local Health District

“These clients had been safe in hospital, nothing has happened in their care, so why change now?” Manager, Aged Care Unit

Confidence for families in the process and the management of potential risks had to be assured. Just as services shifted the language they used with people with mental health issues in their care and with staff, they also shifted the language they used with families. Units were described and referred to as ‘transitional’ with a discussion about the phase of “acute mental health care finishing”, and that it was time for their family member to be moved to a community setting. This discussion was backed up with assurance that clinical care would continue to be provided, as for many families this is where things had gone awry in the past. On transition, if things did not go well for the person living with mental health issues, they and
their families were assured that they could return to the long-stay unit for assessment at any time. People who are eligible for the PCLI will always need access to clinical community care, but the hospital unit was no longer to be their home, it was to be a place of assessment and transition.

“There will always be a group of clients we should not discharge [from community mental health services], they have a level of illness to manage and may relapse. We will continue to monitor and re-assess.”
Manager, Local Health District

With this in mind the support of a specialist clinical mental health team and access to a community psychiatrist was an essential partnership required to create a safety net for the person who was transitioning. If any issues arose, the MHACPI unit did not have to wait for an urgent review, as the clinical team had clinicians available each day of the week. Today, regular weekly meetings are held to review the clients currently residing in the MHACPI unit, and discuss plans for new transitions.

“The opportunity to talk with the clinical team every week and think together about what else we can do to help these people is invaluable. Every week we spend two hours in a clinical review.” Manager, Aged Care Unit

“We could not offer this service without the continued support of the [clinical] team. We have the specialists in psychiatry working with us and the resident. Working together takes a key skill but the benefit is there.”
Executive, Aged Care Provider

Letter from a carer

“I was asked if I would like my brother to be moved into the aged care unit. It was on a trial basis and his room would be kept for him until this trial month was up. If he was not suitable for the unit then he would go back. You do not have to agree to this move but I felt that I have done the right thing for my brother.

He now has his own room with an en-suite. A glass sliding door looks out onto a garden. This will be unlocked as soon as the fence is completed. The lounge area is bright and sunny and the nursing staff are very caring and understanding. The unit has a warm and homely feeling.

The residents can sit in the lounge area, walk out onto the sunny courtyard and go to their rooms at any time. There is a doctor who is on call and the hospital is only minutes away.

My brother seems more settled since he arrived.”
6. What the PCLI has achieved so far

“If we work together we will be able to achieve this. It’s not about who does it best or who does it better. Let’s get these individuals into a homely environment. Let’s try together and see what happens.” Manager, Aged Care Provider

Despite the challenges discussed above and those that lie ahead, the evidence for the value of the PCLI is in the numbers of successful transitions to date. At December 2017, data from the NSW Ministry of Health indicates that overall there were around 100 transitions to the community from the original group of people identified as “long-stay patients”. Over 40 people with ageing related issues had transitioned successfully at that date. Some of these people may require planned re-admissions to hospital at times for short periods of stabilisation. This is not a failure of the program but is part of the recovery journey for people who have reoccurrence of acute symptoms of illness. What is important is that for many people, they now have a place to call their home which is outside of hospital. The value of the program is also evident from the testimony of those involved:

“One of the ladies that came across from the unit was in hospital for 32 years. Everyone was apprehensive about how it was going to work. We spent some time transitioning her slowly, she would come across for lunch, and then go back, come across again, and spend some time for art therapy…after a couple of visits she asked ‘when can I move in?’” Executive, Aged Care Service

“We know this project is going well. We are using less medications and it is a home like environment. One lady was in hospital for 30 years. She is now in the specialist unit and doing very well.” Clinician, Mental Health Unit

“One lady presented as very [internally] tortured and vocalising a lot on the ward. Moving her on was a great trust of the family. When I see her now she has a look on her face of being comfortable and calm. I have not seen her look this much at peace for a long time.” Clinician, Mental Health Unit

“One man had not spoken for years. Our diversional therapist is in there and working to socialise him with others. He is now conversing at a level that has not been seen before.” Manager, Aged Care Service

“His sister was apprehensive about him coming. She was not sure how it was going to go. She says she is glad she took the leap of faith. She sees him different than he was.” Manager, Aged Care Service
The PCLI has key milestones planned up to eight to ten years. While this report has provided a snapshot of the first years, it demonstrates that lasting change takes time and requires a shared vision of success, distributive leadership, culture change and responsibility and partnership at all levels. Projects which re-shape the future of mental health care go beyond political and funding cycles. They require persistence and a long-term vision of success. They support culture change and a humanistic approach.

It is the hope that society will no longer tolerate people with mental health issues staying in hospital for longer than they need to. The PCLI and new pathways are starting to develop to ensure that extended stays in hospital can be avoided wherever possible. But we are not there yet. For an effective and responsive system, significant funds need to be invested in the community. While the PCLI is a start, more investment is needed to provide clinical community care across the spectrum, and 24-hour support for those who need it. Until this is adequately available across NSW we remain at risk of people being in hospital for far too long.

The roll-out of the next years of the PCLI will involve new challenges including identifying services for younger people in the PCLI cohort. This group of individuals will have different needs to the older people with mental health issues who took part in the first years of the Initiative. For example they may experience significant mental health issues together with drug and alcohol issues, and difficulty expressing themselves in a way that is safe and easily understood.

“There are some people we really worry about [living in the community]. There can be a lot of substance misuse as well as intellectual disability.” Manager, Local Health District

As with the first transitions, those implementing the Initiative will need to take an individualised approach and develop tailored services to meet the needs of these people. Culture change and adapting to new ways of working will remain key challenges for the services that are affected by the PCLI, but are part of a long-term change management process that will continue until they are embedded as ‘business as usual’. Much of the groundwork has already been laid and people are optimistic about the future.

“In the new world we would have more purpose-built wards, with things like group rooms, kitchens and a lot more Occupational Therapists. We will always need a ward for people that need it.... but that unit will get smaller. The PCLI has given us the opportunity to think outside the square and look at what else we need.” Manager, Local Health District

Participants at a PCLI Dialogue Day, April 2016
8. A history of mental health institutionalisation in NSW

“…the house was meant to keep them in. Once they came, they never left.” Madeleine Roux, Author ‘Asylum’

The establishment of the PCLI follows many decades of reviews and reports pushing for the deinstitutionalisation of mental health care in NSW and for further investment in and development of community-based care options. A summary of landmark reforms that paved the way for the PCLI is provided below.

8.1 Historic inquiries into deinstitutionalisation

In the 19th and 20th centuries in Australia and abroad ‘asylums’ were the main places of care for people with severe mental health issues. Australia had around 30,000 acute care psychiatric beds in the 1960s, but by 2004 this number reduced to 8,000.16 This change was brought about by improvements in the treatment for many mental health issues through pharmaceutical advances, changes in perception about human rights for people experiencing mental health issues (including the separation of services for those with an intellectual disability), and unfavourable audits of stand-alone psychiatric institutions (former Schedule 5 hospitals).17 Support and evidence for a shift to community-based care was widespread, however the roll out of adequate community-based resources was slow to follow, meaning people with mental health issues continued to be frequently and repeatedly admitted to hospital, including for long-stays.

In 1983, David Richmond led the NSW Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled.8 The investigation focused on Schedule 5 psychiatric hospitals, public hospitals, community health and services provided by non-profit organisations, with the key term of reference “to determine the appropriate nature, extent and distribution of services for the psychiatrically ill, psycho-geriatrics and the developmentally disabled”.18 The resulting recommendations, known as the Richmond Report, advocated for a gradual process of de-institutionalisation and concurrent growth of equivalent community care through transfer of funding from hospitals to the community. Key recommendations and principles of the Richmond Report included:

- existing Schedule 5 or stand-alone psychiatric hospitals should be reduced in size
- funding should be provided to services which maintain clients in their normal community environment
- people should have many opportunities for social and physical contact in the community, regardless of their level of physical, intellectual or social functioning
- the care of people experiencing mental illness or a developmental disability should not be segregated from other aspects of health services.

These recommendations were controversial at the time. In some locations public meetings were held, some health staff participated in strikes and one country town closed down for a day in protest.20 Despite the NSW Government’s broad adoption of these policies in 1983, a new government abandoned the Richmond Report directions and undertook its own review led by Dr William Barclay who advocated that institutions close by a process of evolution.21 By the mid-1990s it was clear people with mental health issues still did not have adequate accommodation and employment support.

Published in 1993, the Report of the National Inquiry Into The Human Rights Of People With Mental Illness (known as the Burdekin Report), highlighted the inadequacy of community care thus far to provide basic human rights to people with a mental illness.22 Led by then Federal Human Rights Commissioner Brian Burdekin, this inquiry differed from others by highlighting service failures from a humans rights based approach rather than describing the mental health system and its parts. Burdekin concluded, after extensive consultation with people with a lived experience of a mental health issues that:
• “people with a mental illness suffer from widespread, systemic discrimination and are consistently denied the rights and services to which they are entitled”

• “the level of ignorance and discrimination still associated with mental illness and psychiatric disability in the 1990s is completely unacceptable and must be addressed”

• “the savings resulting from deinstitutionalisation have not been redirected to mental health services in the community”

• “the inadequacy of existing community mental health services to treat, care for and support people with mental illness living in the community is disgraceful. Those services which do exist are grossly underfunded and underdeveloped”.

In 2005 the Human Rights and Equal Opportunity Commission together with the Mental Health Council of Australia and The Brain and Mind Institute released a report “Not for Service” highlighting the inadequacy of community-based mental health care. After wide consultations, including open community forums in each state and territory, individual meetings, written submissions and two community surveys, the inquiry reached the following conclusion:

“The process of deinstitutionalisation has not been accompanied by corresponding supports for mentally ill people to live in the community. This has left many people with a serious mental illness without the help they need.” Dr Sev Ozdowski OAM, Human Rights and Equal Opportunity Commission.

The assessors concluded that “the system, as it currently operates may result in a failure to provide basic medical and psychological care and inappropriate use of short term seclusion, confinement and over-reliance of sedating medications.”

The consumer and family and carer movement, which was already working for change, started to gain momentum and reiterated their concerns about increased community services throughout the sector. Since the 1980s, people accessing mental health services and their families and carers began loudly demanding reform and system transparency, which has continued to this day.

“If someone has a heart attack, they are not kept in hospital for the rest of their lives in case they have another one, even though it is quite likely. They have their
Despite the growing activism from consumer groups for more community care, a number of people in NSW remained in hospital long after they needed to. Individuals and stakeholders including the NSW Public Guardian voiced their concerns about this situation.

In 2012 the NSW Ombudsman commenced an inquiry into the number of people living in mental health facilities in NSW. A review of files identified 95 people at a point in their recovery where they were ready to leave inpatient facilities for a more connected life in the community, but who were not able to make this transition. Consultations with around 300 government and non-government stakeholders including mental health experts, consumer groups, advocates and peak agencies identified a number of barriers preventing people from making this transition, including:

- no discharge planning occurring for almost one third of the people who were well enough to leave hospital
- the views of mental health staff about the best interests of the patients, as well as the views of inpatients themselves
- limited knowledge of support options available
- long periods of time between staff making a referral to a service and following it up.

In concluding, the Ombudsman advocated for people with severe mental health issues and psychiatric disability to access disability services through the Disability Services Act to increase their access community services.

8.2 Living Well and the NSW Government response

By the time of the NSW Ombudsman’s report in 2012, the appetite for mental health reform was at a national high. At a state and national level Mental Health Commissions were soon established to track the progress and increase the accountability of mental health reform. In the founding legislation for the NSW Commission (The NSW Mental Health Commission Act, 2012), the development of a strategic mental health plan was mandated. The resulting plan, called Living Well: A Strategic Plan for Mental Health in NSW 2014-2024, provided a ten-year vision for improving the mental health system in NSW, with a focus on better supporting people experiencing moderate to severe mental health issues to remain well in the community and lead their own recovery. The NSW Government adopted Living Well in December 2014 and under the Government’s Mental Health Reform 2014-2024 response it has since invested in a number of initiatives to strengthen community-based care, including increasing specialist clinical mental health services in the community, expanding psychosocial community supports and assisting long-stay mental health patients to move to the community under the PCLI. The implementation of these and other Living Well reforms is being overseen by the Mental Health Reform Taskforce, led by the Secretary of NSW Health.

8.3 Where we are now

Long lasting mental health reform, or any health system change, is not possible without political support, policy change and alignment with likeminded initiatives across sectors. A number of broad national and state reforms currently align with Living Well and the ethos behind PCLI to promote autonomy, individual choice, recovery in the community, and the right for people experiencing mental health issues to live a contributing life.

On July 2015, 31 Primary Health Networks (PHNs) were established by the Commonwealth Government to increase the efficiency and effectiveness of medical services, and to improve the coordination of care to ensure people get the right care in the right place at the right time. PHNs were assigned six key priority areas including mental health and suicide prevention. PHNs are now the key vehicle for local-level action on mental health and suicide prevention, including providing leadership, embedding stepped care approaches and driving local service integration. There are ten PHN mental health lead sites across Australia, which will document and evaluate their approaches to stepped care, regional planning and integration, and delivering low intensity services. Of these ten sites, some will deliver innovative approaches to preventing suicide, as well as provide services for youth and
adults with severe and complex mental health conditions.\textsuperscript{35}

NSW is also the site of a suicide prevention trial called Lifespan, which is being led by the Black Dog Institute with funding from the Paul Ramsay Foundation. The trial involves the simultaneous implementation of nine evidence-based suicide prevention strategies, with the aim of reducing suicide deaths and suicide attempts by 21 per cent and 30 per cent respectively. This ‘systems approach’ is being trialled in four NSW locations and will likely boost the accessibility of community-based suicide prevention services.

Significant disability reforms that begin to address part of those concerns raised by the NSW Ombudsman in 2012 are also being rolled out under the National Disability Insurance Scheme (NDIS). This means, people with a psychiatric disability will be offered support under disability funding if their illness affects their communication, social interaction, learning, mobility, self-care or self-management and the impairment affects or is likely to affect the person’s capacity for social or economic participation. The NDIS uses the term ‘psychosocial disability’ to refer to disabilities that arise from mental health issues.

From 30 June 2018, the NDIS will be available across all of NSW.\textsuperscript{36} People’s experience of accessing the NDIS and the assessment process has been mixed so far, however some limited success has been reported that long-stay patients have had success in accessing support packages. However promising some stories have been, concerns have been raised with the Commission by mental health peak bodies and stakeholders and others about the implementation of the NDIS for people with mental health issues including:

- NDIS eligibility criteria for people with psychosocial disability
- the real numbers of people affected by psychosocial disability (there are concerns that the NDIS estimates are too low)
- variability of assessment outcomes for people with a psychosocial disability
- pricing of psychosocial supports
- supports for carers of people with psychosocial disability
- managing workforce and supplier market transitions.

The Commission is keeping abreast of these changes, and will continue to advocate on behalf of people with lived experience of mental health issues, their families and carers to ensure that those eligible can access packages under the NDIS. Mental health reform will continue to require patience and financial commitment to bring about the necessary cultural and leadership change. Programs such as the PCLI have a person-led philosophy and it is up to each of us involved in mental health reform to undertake our work in co-designing and co-producing the outcomes for people that they aspire to and deserve.

2. NSW Ministry of Health, Unpublished, 2016


7. Ibid.


10. NSW Ministry Of Health, Dialogue Day One, Unpublished, 2015


14. Ibid.


17. Australian Government, Select Committee on Mental Health, First Report, March 2006


19. Ibid.

20. Ibid.


23. Ibid.


25. Ibid.

26. Ibid.


