



**Mental Health Commission**  
of New South Wales

# *Living Well:*

## Community perspectives of change



## ACKNOWLEDGEMENT

As part of the Commission's commitment to bringing the voice of lived experience and of the community into its work, we held an online community survey in October 2016. We wanted to learn what changes people were observing or experiencing in mental health supports and services. A diverse group of 1,510 people responded to the survey, including people who had used mental health services for themselves or who supported a family member or friend, as well as people who provided mental health services or supports and those who funded and managed services.

While the survey respondents represent a small section of the community, nevertheless, the insights they have shared are an invaluable way for the Commission to 'take the temperature' of mental health reform in our state. We would like to thank all participants for taking the time to share their thoughts and observations, which are invaluable as the Commission continues its work to improve the mental health system and the mental health and wellbeing of all people in NSW.

Preferred citation:

Mental Health Commission of NSW (2017), *Living Well: Community perspectives of change* 2016. Sydney, Mental Health Commission of NSW

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ISBN: 978-0-9945046-7-8

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*Wellbeing match workshop , International Initiative for Mental Health Leadership Exchange, February 2017*





# Survey results at a glance\*

## COMMUNICATION ABOUT *LIVING WELL* AND MENTAL HEALTH REFORM IN NSW

Of the 1,510 people who participated in the Evidence of Change survey, 64 per cent had heard about *Living Well*. Private sector participants had the least awareness (50 per cent).

Thirty one per cent of respondents reported there was a 'lack of communication and information' about Commonwealth reform programs such as the National Disability Insurance Scheme (NDIS) and Primary Health Networks (PHNs), and other NSW reform programs.

## EXPERIENCES WITH IMPLEMENTATION OF *LIVING WELL*

Thirty per cent of respondents have been involved in **discussions** related to the implementation of *Living Well*, with 38 per cent involved in **activities** related to implementation. Just over 27 per cent were aware of what was happening in their local area in relation to *Living Well*, with most reporting successes and positive experiences. Private sector respondents reported the least involvement in implementation.

## PERCEPTIONS OF CHANGE

Overall, the findings indicate the community has seen some evidence of **improvement** across the 12 priority areas (average of 26 per cent), with the greatest improvement evident in service providers' focus on recovery (34 per cent). For most the experience has been of **no change** (average of 37 per cent), with some reporting **worsening** in priority areas (average of 13 per cent), particularly in the **accessibility and responsiveness** of services (23 per cent). Nearly a quarter (average of 23 per cent) reported they **don't know** what is happening in reform priority areas.

\*Findings from the Evidence of Change survey conducted during 26th September – 14 October 2016.

## OUR COMMUNITY SURVEY

*Living Well: A Strategic Plan for Mental Health in NSW 2014-2014* was adopted by the NSW Government in December 2014. Its vision is to enable the people of NSW to have the best opportunity for good mental health and wellbeing and to live well in the community on their own terms. Implementation of *Living Well* is now a shared responsibility across government agencies and it is the NSW Mental Health Commission's role to monitor and report on progress with implementation. The perspectives of the community and individuals are essential to an informed understanding of how reform is progressing.

The Commission conducted a survey from 26 September to 14 October 2016 to gain an understanding of the community's knowledge of *Living Well* and experience of the Plan's implementation and progress. This report summarises the main findings from the Evidence of Change survey, in which 1,510 people participated. It presents the perspectives of people with lived experience of mental health issues, families and carers, and people working in the sector, on evidence of progress towards reform. The findings can be used to inform how agencies approach and communicate ongoing reform efforts.

The summary report is accompanied by a more detailed technical report on survey methodology, respondent profile, analysis and findings, available on the Commission's website.

## WHO PARTICIPATED?

There were three main groups of people who participated, accounting for 92% of survey respondents:

- mental health practitioners/clinicians at 33 per cent
- people with lived experience of mental health issues at 32 per cent
- carers of a person with lived experience at 27 per cent

Other members of the community accounting for the remainder (Note that respondents were able to choose multiple roles).

There was also a strong response from the Aboriginal community, accounting for 4.8 per cent of respondents, which is a rate higher than the proportion of Aboriginal people in the NSW population at 2.9 per cent. This comparatively higher response rate of Aboriginal people means that their voice can be more clearly heard, which is integral to mental health reform in NSW.

## FAMILIARITY WITH *LIVING WELL*

Being familiar with *Living Well* is an important indicator that people are aware of the mental health reforms that it outlines.

Overall, 64 per cent of respondents had heard about *Living Well* prior to this survey. This differed across groups, with knowledge of *Living Well* highest among the not-for-profit/community managed sector (76 per cent of respondents), followed by the government sector (71 per cent), consumer and carer respondents (63 per cent) and then the private sector (50 per cent).

## EXPERIENCES WITH IMPLEMENTATION OF *LIVING WELL*

Respondents were asked about their experiences with the implementation of *Living Well*, focusing on five specific areas:

1. Involvement in discussions
2. Involvement in activities
3. Using *Living Well* to guide, advocate for and/or promote change
4. Awareness of reform champions
5. Awareness of local action

Figure 1 outlines the percentage of respondents who reported involvement across these five areas. Those from the private sector reported the lowest level of involvement with the implementation of *Living Well*.

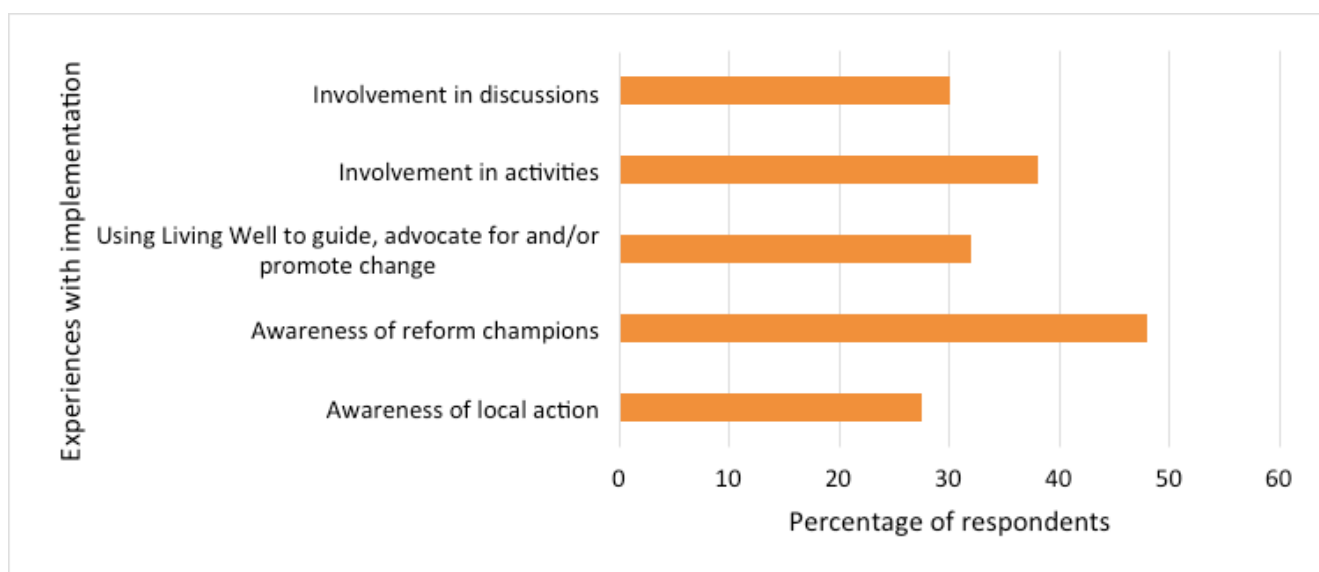


Figure 1: Respondents' feedback on experiences with implementation of *Living Well*

### Respondents' own words: Local implementation

Of the 27.5 per cent of respondents who reported awareness of local implementation of *Living Well*, 71 per cent provided feedback on the types of activities that were being undertaken by their organisation and/or local organisations. Of these, most (96 per cent) reported activities that were **successes and positive experiences**, while a small group (9 per cent) reported **barriers and negative experiences**<sup>1</sup>.

Figure 2 summarises the activity areas included under 'successes and positive experiences'.

**Services and programs** included activities that reflected good practice, such as increased involvement of consumers and carers in decisions about care and service delivery; recovery and person-centred practices; increased collaboration between services; new services and models of care; and increased holistic care:

- “I am a mental health clinician who works with people with a major chronic illness. We ensure all our clients are linked with general practitioners (GPs). We provide client centred care and provide mental health support identified in assessment and advocate for more intensive support when our team is unable to provide this support. We work under a self-management model.”
- “We were able to secure the services of an exercise physiologist 1 day a week at our facility. Patients are really enjoying the exercise sessions, supervised walks and nutritional advice.”
- “[Our service has been] completing consumer wellness plans with all consumers. [Our] service is recovery focused and strengths based.”

<sup>1</sup> Note that respondents often included multiple themes in their feedback.

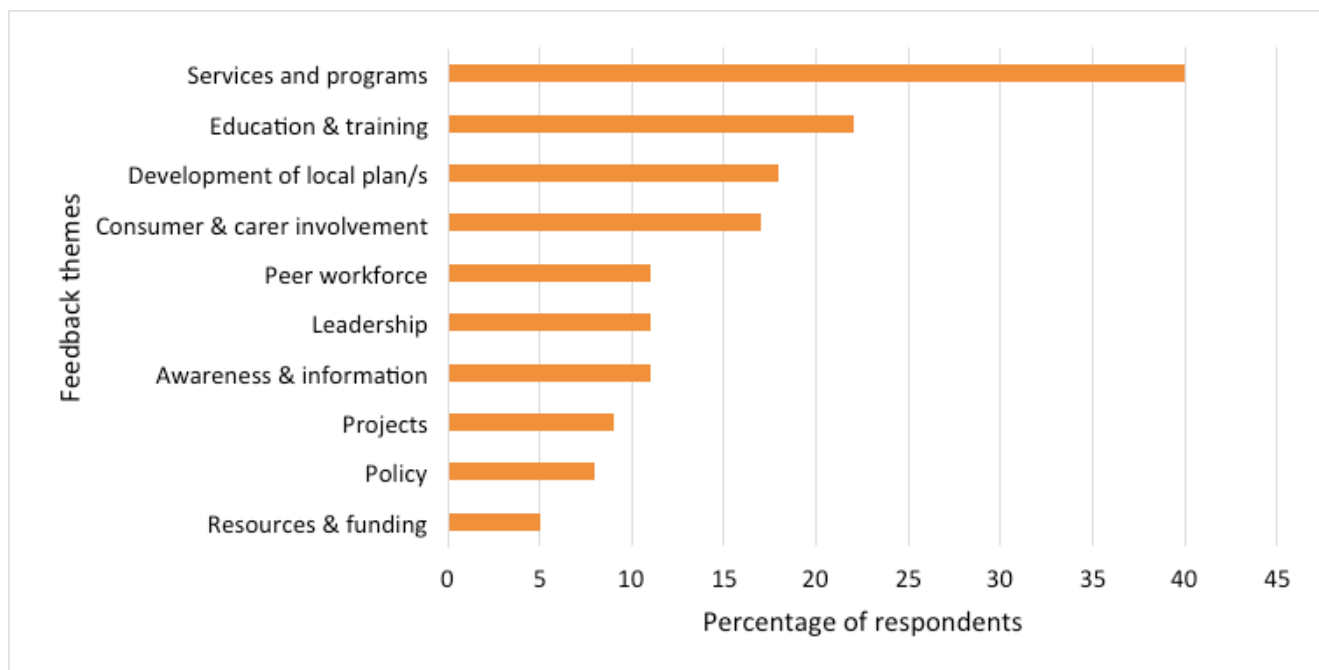


Figure 2: Activities related to Living Well undertaken by own organisation and/or local organisations – ‘successes and positive experiences’

**Education and training** activities included initiatives for service providers, consumers, carers and families, and an increased focus on mental health issues in professional and community initiatives such as:

- “Increased training for trauma informed care”.
- “Working with NGOs to deliver MHFA [mental health first aid] training to community members and hospital staff”.
- “Staff ... participated in recovery training to better understand how to implement these principles in our work with clients.”

Many described the **development of local plan/s** that incorporated *Living Well* reform principles, as well as the inclusion of consumers, carers and staff in these processes:

- “Living Well has been a source document for (our service’s) mental health reform process. We have used it to inform the development of the... sub-acute unit model of care and it remains a reference for on-going discussions about the sub-acute unit not being used as an overflow unit for the acute unit, but as a viable option for early intervention to avoid having to meet the current criteria for inpatient admission”.

Opportunities for increased **consumer and carer involvement** were noted in both care decisions and service delivery, as well as strategic planning, policy development, training, quality improvement and/or governance processes:

- “I am ... a consumer who has been recently unwell. I was and am very lucky in that the people who look after my mental health also believe in having a plan that I am comfortable with.”  
(Read the full comment at the end of this document)
- “I have been ... involved with develop[ing] (a local) Mental Health 10 year Strategic Plan 2015-2024. I am currently employed as a health peer support worker under the funding of [the] Living Well, Living Longer Project to emphasise the importance [of] improving consumers’ physical health outcomes in (this district).”



And there were many who described development of the **peer workforce** and more positive attitudes regarding the peer workforce:

- “I have lived most of life by the seat of my pants. I have been a consumer/client at the very place that I now work for. I am a trained and certified Peer Specialist which makes me a very valuable employee. I have advocated for many people, educated from my life experience...”
- “My son has a lived experience of mental illness and is now a consumer involved in working for mental health services in various roles full time. He speaks well of this initiative.”
- “[I have observed] development of [the] peer workforce and planning for [a] youth specific peer workforce”.

Further information on the remaining themes outlined in Figure 2 is available in the technical report.

While a minority of respondents reported they were involved in or aware of the implementation of *Living Well*, those who were aware of local action regarding implementation predominantly reported successful and positive experiences.

*Check-up from the Neck-up, Sydney Easter Show, April 2017*





## PERCEPTIONS OF CHANGE

Respondents were asked to indicate whether they had seen changes across a range of priority issues since the NSW Government adopted *Living Well* in December 2014. They were then asked whether these issues had improved, stayed the same or worsened.

Most respondents reported things were **the same** (average of 37 per cent), followed by **improved** (average of 26 per cent), **worsened** (average of 13 per cent) and nearly a quarter of respondents chose **don't know** (average of 23 per cent).

Those from the not-for-profit/community managed sector chose 'improved' more (average of 33 per cent) than other respondents, while those from the private sector chose 'improved' the least (average of 19 per cent). Private sector respondents chose 'worsened' (average of 21 per cent) and 'don't know' more (average of 28 per cent) than other respondent groups.

Respondents' perceptions of change in *Living Well* priority areas are summarised in Figure 3.

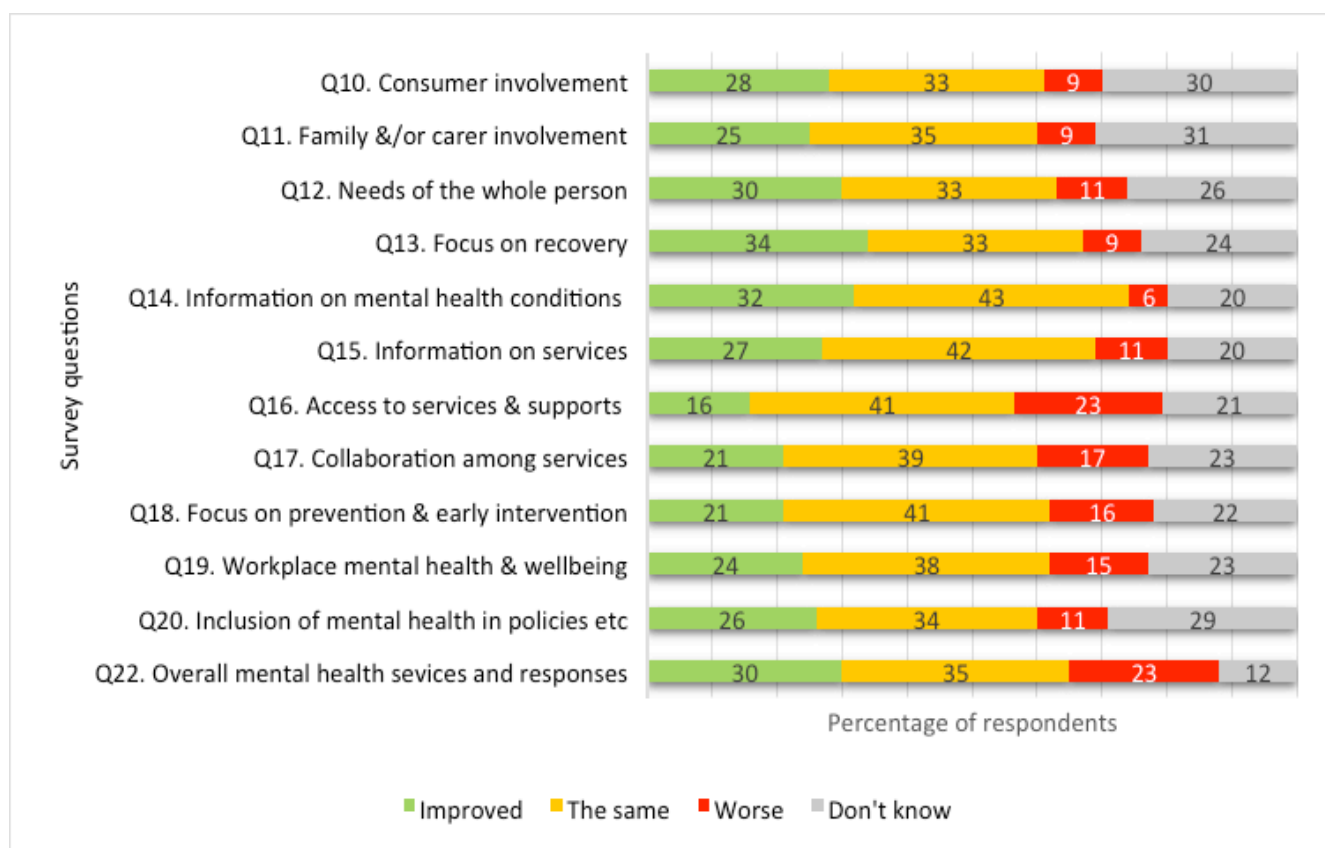


Figure 3: Respondents' perceptions of change in *Living Well* priority areas






## Respondents' own words: Changes

Survey respondents were also asked three open-ended questions about their perceptions of change.



The first question asked **what other positive changes have you seen since the Government's adoption of Living Well?** Of the 35 per cent of respondents who provided feedback (n=521), 58 per cent described **successes and positive changes**, while 54 per cent described **barriers and negative changes**<sup>2</sup>.

### Positive changes

The positive change most frequently reported was increased awareness and information about mental health issues (33 per cent) followed by, improved and/or good practices (21 per cent). For example, people said they had noticed:





-  *"Greater awareness and understanding in the community; less stigma; people more pro-active in addressing [their] own mental wellbeing".*
-  *"Improved media coverage, more employer willingness to understand and support during crisis periods."*
-  *"Increased consumer work force in local health district community teams."*
-  *"The wider community and other agencies have become much more accepting and realise the need for early intervention and using person-centred approaches to recovery."*
-  *"Local area health services are developing new models of care for recovery services".*

Many noted they were not sure if the positive changes were due to *Living Well* or to general progress in mental health care:

-  *"Have not heard of Living Well however things have improved in the ten years since my brother tried to commit suicide and the limited help that was available at that time."*
-  *"I just know that my consumer son has been able to find more opportunities for employment within mental health services".*

### Barriers and negative changes

Of those who reported barriers and negative changes, nearly 14 per cent reported that things are worse and that poor practices still occur, with close to 11 per cent attributing barriers and negative changes to poor leadership. Nearly eight per cent of respondents reported loss of services and funds:

-  *"...since 2015 we have seen a reduction in the number of frontline mental health staff. This means staff are too overworked to be truly recovery focused. Or too inexperienced ... leading to a focus on people with the less disabling conditions at the expense of those with the severe and enduring issues."*
-  *"I have been a consumer of NSW mental health services for 20+ years....My experience over the past few years is that services are limited and often only available in a crisis. Preventative services are limited, services are disjointed and the level of support available is insufficient."*
-  *"Mental health assistance in regional areas is getting worse. Acute and persistent patients cannot access help from non-government organisations (NGOs)."*
-  *"Loss of mental health services in the community as new money goes to private and NGO (sectors) which just don't provide the services to people who are challenging and don't provide seamless services. More are falling through the cracks."*

## EFFECTS OF BROADER REFORMS

The second question asked respondents if they had **any observations about the effect of Commonwealth reform programs or other NSW programs on the current status of mental health services in NSW**. Forty one per cent of all respondents provided feedback (n=616). Of those, 72 per cent reported **barriers and concerns**<sup>2</sup>, 20 per cent reported **successes and positives** and 22 per cent reported either **no change, too early to tell or don't know**<sup>2</sup>. The National Disability Insurance Scheme (NDIS) was the most frequently mentioned reform program (39 per cent), followed by the Primary Health Networks (PHNs) (16 per cent).

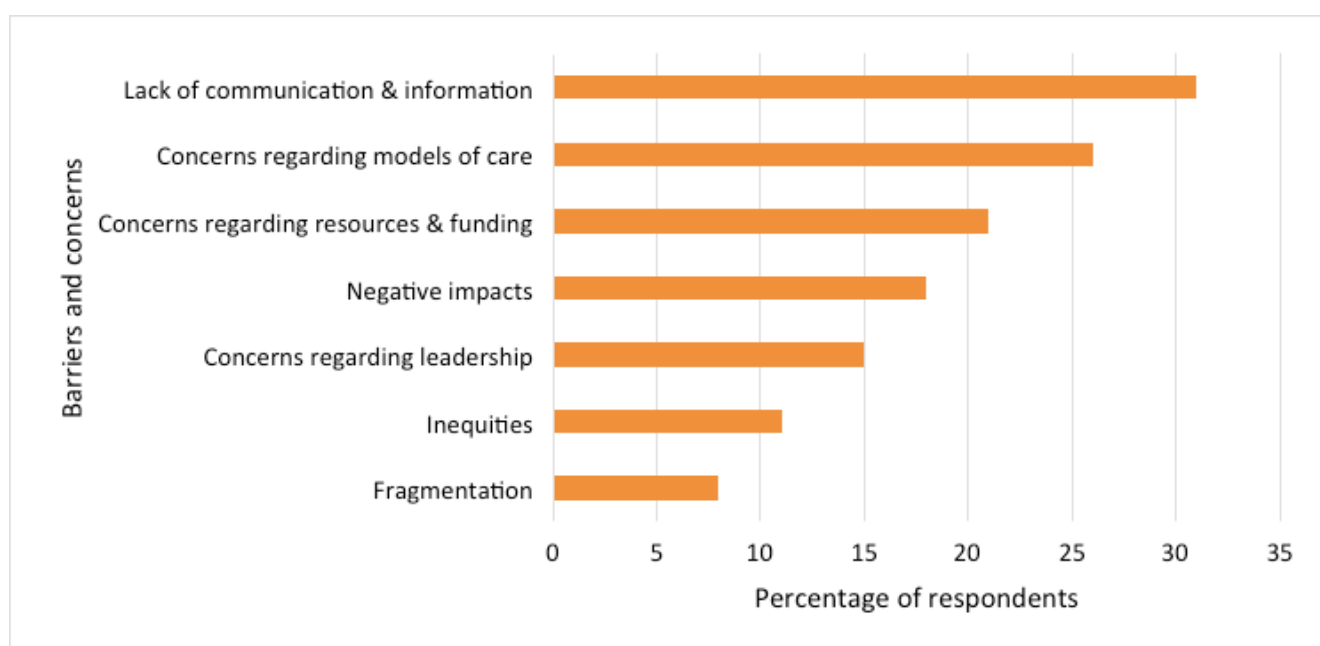


Figure 4: 'Barriers and concerns' most frequently reported by respondents

### Respondents' own words: Effects of broader reforms

Of those who reported barriers and concerns, 31 per cent reported a lack of communication and information about Commonwealth reform and other NSW programs (31 per cent), particularly how the roll out of the NDIS and PHNs will affect consumers, carers and their families and existing services:

“... I can see a mental health nurse now through my GP and psychiatrist under the Mental Health Nurse Incentive Program, and I now find out that their funding is going to be [reviewed by the PHN]... These nurse[s] were able to see me and others in the long term. I am afraid that once again a good service, which is cheap and means I don't go to hospital, is going to go.”

Respondents were also concerned about the models of care being adopted by these reform programs (26 per cent):

“Change inevitably causes tension, but the language of the NDIS ‘permanent, severe, persistent’ and the necessity to prove your incapacity to establish eligibility is at odds with the recovery model we are promoting.”

Concerns were also expressed about resourcing underpinning reform efforts (21 per cent):

“I am concerned that mental illness is not getting adequate funding under NDIS and that people are missing out and suffering...”

<sup>2</sup> Note that respondents often included multiple themes in their feedback.

Worries about negative impacts of the changes (18 per cent), concerns about leadership (15 per cent), inequities (11 per cent) and fragmentation (8 per cent) are reflected in the comments below:

“One risk here, I suspect, is that there will be an increase in the unevenness of services across the state, in relation to initiatives that were in place such as the Mental Health Nurse Incentive Program; in some regions this seems to have transitioned across and to be well supported by PHNs, and in others support has been lacking. I suspect there are similar concerns regarding Better Access, and so on.”

Of those who observed successes and positives, improved models of care were noted by five per cent, along with positive impacts by three per cent:

“NDIS scheme is a big step and long overdue”.

“PHNs are doing a valuable job and, in my local area have made a big difference with the Partners in Recovery Program and genuine consumer and carer participation and representation.”

Overall, respondents indicated it was hard to know which reform initiatives were contributing to change. They indicated a ‘whole of reform’ perspective is needed, not just a focus on individual programs. They wanted leaders at national and state levels to ensure reforms are complementary and work together, and to provide more information about how programs work, including how they intersect. Finally, respondents wanted more accountability regarding how changes are being implemented and how they are performing.

## OTHER EMERGING ISSUES

The third question asked respondents if there was **anything else you would like us to know?** with 33 per cent (n=505) providing responses. Eighty one per cent of these respondents reported **barriers and concerns** and 17 per cent reported **successes and positives**.

Of those who reported barriers and concerns, their main worries were **models of care** (47 per cent), **leadership** (27 per cent) and **resourcing and funding** (24 per cent):

“There remains a considerable degree of resistance to working in a recovery based framework with adoption of this slow in some units. There is also a level of wariness regarding implementation of Living Well due to anticipated significant increases in numbers of very unwell consumers presenting to community and hospital based mental health services with no corresponding increase in resources. The change management process should include high levels of consultation with staff at all levels, be thorough and sensitive to the human process of change, not just the practical aspects of the changes. Make communications regular, clear and relevant to recipients”.

“NSW Health is focused on hospital-based services - when keeping costs down requires an extensive network of Community-based services to improved patient flow. But Community-based services are historically Federally funded, and no one in either level of government seems to have the maturity of political will to improve this dichotomy”.

People were also concerned about **negative impacts** of current mental health systems and practices (19 per cent), lack of **communication and information** (15 per cent), **inequities** (9 per cent), **barriers for regional, rural and remote communities** (7 per cent) and **fragmentation among services** (5 per cent).

They wanted to see **increased accountability** (19 per cent), **increased resources** (16 per cent), **increased involvement** of consumers, carers and service providers in reform activities (12 per cent) and **increased workforce training** (5 per cent).

“There are lots of funded programs, lots of great objectives but very little accountability on the ground or real care for those actually affected by mental illness and those caring for them ....”

The findings indicate that the overall dominant perception is that things have not changed. However, some respondents had observed either positive or negative changes or both. Significant concerns were expressed regarding leadership, communication, resourcing of reform activities and the need for enhanced accountability for reform implementation and performance.





*Perinatal and infant mental health match event, International Initiative for Mental Health Leadership Exchange, February 2017*





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