INQUIRY INTO THE MANAGEMENT OF HEALTH CARE DELIVERY IN NSW

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Date Received: 28 April 2017





Submission for the Inquiry into the Management of Health Care Delivery in NSW to the Public Accounts Committee 28 April 2017

BEING

BEING is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.

BEING's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Our work is guided by eight principles:

- Principles of recovery underpin all our work
- Recognition of the importance of a holistic approach
- Collaboration and team work
- Flexibility, responsiveness and innovation
- Consultative and participatory processes that have consumers at the centre
- Promoting equity and positive images to address discrimination and prejudice
- Accessible and approachable for all
- Promotion of professionalism and quality practice

BEING is an independent non-government organisation that receives core and project funding from the Mental Health Commission of NSW.

Find out more at http://www.being.org.au

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Acknowledgements

BEING would like to thank the people who have generously shared with us their experiences and views.

Cover photo: http://maxpixel.freegreatpicture.com/Of-Data-In-Construction-Of-Control-Caution-Cone-1776642



BEING would like to thank the Public Accounts Committee for providing the opportunity to give feedback regarding the management of health care delivery in NSW.

The information provided in this submission is drawn from consultations with people with a lived experience of mental illness, and relevant research.

a) The current performance reporting framework for monitoring the effectiveness and efficiency of health care service delivery in NSW;

People who use mental health services in NSW have very limited access to reporting on data relating to mental health service delivery. They are not able to access information about the quality of services they are using or information relating to issues identified as human rights concerns, such as the rates of seclusion and restraint in a particular unit or district. Without this information people are unable to make informed decisions about their services and are limited in their ability to identify issues, provide feedback and advocate for change. The current lack of transparency around mental health service reporting hides problems from the public eye, and this is preventing the improvements to service we urgently need. This is recognised by people with mental illness, who told us they want far more access to performance reporting than is currently available.

Of the areas in which people wanted more reporting, the most commonly mentioned was mental health consumer feedback and experience of service. This information has been collected for some time, first by the MH-CoPES survey, and currently by the Your Experience of Service (YES) survey. The YES survey was developed in consultation with service users and is used around Australia, and we congratulate the Commonwealth Department of Health and NSW Health for their efforts encouraging the use of this measure. However, offering the survey to consumers of health services is not mandated in any legislation, and as a result varies widely between health districts. In addition, the report of the results of YES is not made publicly available.

If YES were to be widely administered and that data were publicly reported, it would be a powerful force to effect change in mental health services. The NSW Mental Health Commission's Living Well plan commits to providing effective services in partnership with people who live with mental illness¹, however collecting information

¹ NSW Mental Health Commission (2014). Living Well: A Strategic Plan for Mental Health in NSW. Sydney, NSW Mental Health Commission, p 9.



from people is only one part of this process. In order to be successful, people must have access to that information and play leadership roles in improving those services.

Other topics people wanted increased transparency on were the number of hospital admissions, the number of peer workers at hospitals, the time between referral and assessment, the physical health status of people with mental illness, and the ratio of clinicians to consumers in mental health services. Much of this information is already collected, but not reported or even centrally monitored to our knowledge. If reported, this information would demonstrate the current gaps in mental health services, allowing more effective service delivery and increasing our understanding of who seeks treatment and the obstacles to doing so. One person told us they wanted to know:

Ratio of clinician : consumers - identifies where MHS are under resourced - where staff are supporting 50 or 60 people the care is less efficient and poor recovery focus; staff are tired and experience burnout - a major problem in mental health care where each individual requires a staff person who is caring and professional in their work.

- Mental health consumer, April 2017

An urgent reason to provide more performance reporting is that the reporting itself may improve the outcomes of people with mental illness. Some people have a high level of distrust of mental health services, often due to historically traumatic experiences of interactions with services, and one person told us the transparency demonstrated by public reporting would help repair this. Reporting would also highlight the many people who have positive experiences with the mental health system, giving hope to those who feel there is no help. One person we spoke to suggested recovery stories should be a key part of reporting, as these stories would improve the effectiveness of service delivery.

In addition to the lack of service-related performance data, there is a lack of reporting about the performance of each LHD. Each Local Health District agrees to Key Performance Indicators with the Ministry of Health as a component of their funding agreement, however their performance on these targets is not publicly reported.

Recommendations

• Legislate monitoring of mental health consumer experiences. This could be done by altering the Mental Health Act 2007 to include the collection and the reporting of the Your Experience of Service (YES) survey.



- Publicly release information collected on mental health services, including data concerning admissions, peer workers and the ratio of clinicians to consumers.
- The Ministry of Health publically releases LHD data around the Key Performance Indicators set by the Ministry of Health.

b) The extent to which efficiency and effectiveness is sustained through rigorous data collection, monitoring and reporting;

As mentioned above, BEING recommends increased transparency in data reporting. Not only would this increase efficiency, but it would bring NSW in to line with best practices of mental health reporting in other states. The Victorian Mental Health Act 2014 makes reporting of information to the Chief Psychiatrist mandatory, in areas such as seclusion and restraint, electroconvulsive therapy and reportable deaths. The Chief Psychiatrist is then required to publish an annual public report about the provision of mental health services. This emphasis on reporting should be replicated in the NSW Mental Health Act, which currently has very few reporting requirements.

Increasing the reporting of data would have the added impact of motivating services to monitor and improve their data collection. Having accurate and available data is vital to improving services.

Recommendation

• Alter the Mental Health Act 2007 to be aligned with contemporary thinking about Mental Health legislation and transparency as has been done in other states in relation to their Mental Health Acts. These require public reporting on major issues in mental health services, including seclusion and restraint and electroconvulsive therapy.

c) The adequacy of the provision of timely, accurate and transparent performance information to patients, clients, health providers and health system managers;

Of the people we spoke to, none were provided with any information about the performance of the health services they were accessing. This is not surprising given how little information is publically available. However, without this information people are unable to make informed decisions about the services they wish to access and cannot advocate for change in the services they are using.



The peer workers we spoke to had more access to performance information, and hence more ability to advocate for change. The following example demonstrates how performance information can be transformed into change, when it is available:

"A couple of years ago 3 people approached me in one week distressed that they had been discharged from the service without knowledge. I met with the team leader and we reviewed the checklist we had developed previously and a plan was implemented to ensure all staff were aware of and using the checklist which has as [sic] the first step to discuss a plan for discharge from the service with the consumer. Two of the three were registered back with the service with the third recognising he would be ok without the MHS and he was comfortable with the re-entry process (that had not been explained to him)."

- Peer worker, April 2017

However, BEING would like to voice our concern that information access should not be provided at the risk of violating a person's right to confidential medical records. We are particularly apprehensive about the new Health Records system, which makes a person's medical records available to medical and allied health professionals around the country, including those working for external agencies such as insurance companies². We understand the records will have an opt-in PIN security system, which people are unlikely to set up. The stigma associated with mental illness is still pervasive, and making personal mental health information broadly available will result in discrimination. The right of a person to the confidentiality of their medical records should always be prioritised.

Recommendation

• Develop a reporting system to allow mental health service users to educate themselves about the performance of the services they are using.

d) The extent to which the current framework drives improvements in the health care delivery system and achieves broader health system objectives;

In the current framework, improvements to the mental health system are limited by the lack of transparency in reporting. People told BEING that when they did give feedback, this feedback was often not taken into account in broader planning. This resulted in frustration, reduced inclination to give feedback, and the continuation of problematic systems. More consideration needs to be given to how the data collected

² Dunlevy, S (2017). Optometrists and dentists will know if you've had an abortion or a mental illness in e-health bungle. Daily Telegraph. Retrieved from: <u>http://www.dailytelegraph.com.au/technology/optometrists-and-dentists-will-know-if-youve-had-an-abortion-or-mental-illness-in-health-record-bungle/news-story/b73cccfaf20b6fe96862e9c021b49ae0</u>



can be used to drive improvements, and how people with a lived experience of mental illness can work as partners in this. Participation of mental health consumers in improving mental health services results in better health outcomes and more effective health services³.

The division of NSW into PHNs and LHDs, and the increasing responsibilities placed on local areas, must be complemented by the distribution of information about successful innovations within LHDs. Several people mentioned that information was not necessarily shared between LHDs and organisations. Living Well: a Strategic Plan for NSW, which was accepted by the NSW Government in December 2014 states that "Knowledge exchange must ... include a sharing of experiences and insights, not only data. While innovation in one place may not work in another, sharing of innovation can illustrate what is possible and provide a platform on which to build innovation and reform, rather than starting from scratch."⁴ Currently innovation in the NSW health system is limited by the lack of communication and collaboration between LHDs and other health service providers.

Recommendations

- Review the current processes by which mental health data is translated into action and innovation and implement new procedures to ensure this takes place.
- Implement more avenues for LHDs, PHNs and mental health services to share information about successful innovations.

 ³ Consumer Focus Collaboration (2001). The evidence supporting consumer participation in health. Retrieved from: <u>http://healthissuescentre.org.au/images/uploads/resources/Evidence-supporting-consumer-participation-in-health.pdf</u>
⁴ NSW Mental Health Commission (2014). Living Well: A Strategic Plan for Mental Health in NSW. Sydney, NSW Mental Health Commission, p 115.



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Summary of Recommendations

- 1. Legislate monitoring of mental health consumer experiences. This could be done by altering the Mental Health Act 2007 to include the collection and the reporting of the Your Experience of Service (YES) survey.
- 2. Publicly release information collected on mental health services, including data concerning admissions, peer workers and the ratio of clinicians to consumers.
- 3. The Ministry of Health publically releases LHD data around the Key Performance Indicators set by the Ministry of Health.
- 4. Alter the Mental Health Act 2007 to be aligned with contemporary thinking about Mental Health legislation and transparency as has been done in other states in relation to their Mental Health Acts. These require public reporting on major issues in mental health services, including seclusion and restraint and electroconvulsive therapy.
- 5. Develop a reporting system to allow mental health service users to educate themselves about the performance of the services they are using.
- 6. Review the current processes by which mental health data is translated into action and innovation and implement new procedures to ensure this takes place.
- 7. Implement more avenues for LHDs, PHNs and mental health services to share information about successful innovations.



