Submission No 33

INQUIRY INTO THE MANAGEMENT OF HEALTH CARE DELIVERY IN NSW

Name: Mrs Jennifer Allen

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Legislative Assembly

Public Accounts Committee

E: pac@parliament.nsw.gov.au

Subject: Inquiry into the Management of health Care Delivery in NSW

Dear Sirs,

Thank you for the opportunity to provide feedback on the Management of Health Care Delivery in NSW. This submission will include an executive summary of my recent experience in the Mental Health System (MHS) in NSW. Additionally, recommendations for increased efficiency in data collaboration, consistent consumer monitoring, and improved effectiveness with the inclusion of carers in the consumer's treatment plan. These recommendations will aim to drive improvements in the broader health system objectives.

My name is Jennifer Allen. I am the sister of Bernie Sessions. Bernie suffered chronic paranoid schizophrenia for most of his adult life until he took his own life on 1 July 2017.

Two days before my brother took his own life he was experiencing a psychotic episode. I rang the Mental Health Line who rang the Newcastle Community Mental Health Team (CMHT) to see if they would have a caseworker visit him. The CMHT denied Bernie access to treatment; firstly, they believed he was not acute enough; and secondly, Bernie had been removed from their client list, as he was assessed as being chronic and not severe.

My submission addresses the areas in our MHS that could improve the current framework, and result in the minimisation of lives lost to mental illness.

The specific areas I will address are:

- Recommendations to improve the effectiveness of the Mental Health Helpline
- Recommendations for improvement of the triage framework for involuntary consumers
- Recommendations to mobilise a data sharing system between services
- Recommendations to promote the role of carers in decision making, and treatment plans

Executive Summary

Accessing mental health treatment can be difficult if one is unfamiliar with the available services. The Mental Health Helpine (helpline) has been operational since 2011, and has been successful in enhancing existing services by providing one single number that directly links the consumer to the appropriate care.

The short fall occurs after making contact and being triaged by the helpline professional. The consumer does not speak directly to the service in their area. They are triaged by the helpline, the helpline then relays the information to the service, who then decides whether they are the right service for the consumer. Therefore, when you ring the helpline it is not guaranteed that you will receive treatment, even if you are in crisis.

In Bernie's situation, I called the Helpline and gave a detailed account of my brother's psychotic episode and his chronic loss of reality. The practitioner I spoke with was efficient in establishing what services would be appropriate for Bernie. The helpline made contact with the CMHT in Newcastle to establish a home visit with a caseworker.

The CMHT made the decision not to see Bernie. This decision was made without speaking directly to myself; nor did the CMHT speak to Bernie. The CMHT based their decision on previous notes, and what was relayed by the helpline.

The CMHT failed to acknowledge the psychosocial stressors that had triggered his psychotic episode. Bernie's rental property of 10 years was being sold which became a significant stressor and resulted in Bernie taking his life. Bernie thought the people who were visiting his unit were international crime syndicates who were placing listening and tracking devices on his belongings. Bernie's home had an open house at 5pm the day Bernie took his own life. Bernie was so frightened of the people coming through his unit that he took his own life approximately an hour before the open house commenced. It was the real estate agent that found Bernie.

My mother was Bernie's primary carer and I was his secondary carer, unless mum was unwell then I would take on her role. As we were the people who dealt with Bernie on a day-to-day basis, we knew what behaviours were out of the ordinary for him. I feel that our frontline experience with Bernie was dismissed. The role of the carer is often disregarded when services make decisions about treatment plans, and involuntary treatment or admissions. The perusal of emergency services to place a consumer into involuntary care is governed by the Mental Health Act 2007. It states a consumer must be at risk to themselves or to others. Bernie's behaviour did not put anyone else in obvious harm's way but he was erratic, manic, impulsive, delusional, paranoid, and frightened. Despite our concerns, Bernie was not assessed as being at risk of harm under the premise set by the CMHT, yet Bernie took his life two days later.

This is not the first time we have had difficulties receiving assistance from the CMHT. It is their procedure to first call the consumer, and then arrange for a time for the consumer to come to their place of operation for a discussion around a treatment plan. Bernie needed the CMHT to come to his home due to the severity of his paranoid schizophrenia. Bernie did not have a phone as all of the electrical equipment in his home was covered up, unplugged, or had been thrown out, because Bernie's delusional state had him believe that his equipment was bugged with listening and tracking devices. Bernie only left the house once a week for less than an hour to go to Woolworths with his mother. Any other destination was impossible, as Bernie was severely paranoid. Bernie had not been

anywhere other than his weekly trip to Woolworths since 2014. Prior to that Bernie had not stepped out of his front door at all for over 2 years.

An ongoing investigation into Bernie's refusal for treatment revealed that the CMHT denied Bernie treatment because he was assessed as being chronic, but not severe. If he was assessed as being severe then they would have re-referred him to their service.

It was unknown to us that Bernie had been removed from the CMHT's patient list until the 28 June 2017, the day I rang to seek help. The reason Bernie had been removed from their patient list was because a caseworker went to visit Bernie a few months prior and offered Bernie an NDIS package, which Bernie refused. The caseworker noted that Bernie had his mother to do his washing and shopping. The caseworker did not take into account Bernie's lack of insight into his mental illness, or that Bernie's mother is 76 years old and is also the full-time carer for her 86 year old husband, who has dementia. The caseworker also assumed that Bernie was taking his medication without consultation with Bernie's GP. Further investigation would have revealed that Bernie had not been to see his GP in over a year.

To illustrate my point I would like to draw a comparison between the MHS crisis intervention and the emergency services accessed via triple zero. If a person rang triple Zero for a physical illness and they were refused access to medical help there would be outrage. The question I ask is why is the MHS, in particular emergency response, not based on a similar framework? Mental health crisis intervention is lacking in targeted emergency assistance. A consumer or a carer in crisis needs immediate response from a team who is trained specifically in mental health.

Recommendations

Please see the following list of recommendations that I believe will help drive improvements in the broader health system objectives:

Recommendation 1: The person calling the helpline is triaged and is connected directly to the appropriate service in their area. The caller should be able to speak directly to the service instead of having the information double handled. The helpline's triage notes are immediately relayed to the service for efficiency in decision making.

Recommendation 2: The consumer is seen to that day, if not immediately. Meeting with the consumer while they are in crisis mode is crucial. No carer or consumer should be turned away from accessing treatment at any time.

Recommendation 3: If the call has been made by a carer, and the consumer refuses to be seen, then the carer is seen instead. Being a carer during a crisis is distressing and can have collateral negative impact on their own mental health.

Recommendation 4: Consumer data sharing between services would enhance preventative care and reduce the chance of a consumer developing psychotic episodes. As an example, if a consumer is regularly missing GP appointments to renew medication scripts then an alert is sent to the consumer's caseworker who can visit their client to ensure they are ok.

Recommendation 5: A consumer with a diagnosis of schizophrenia should not be ejected from the MHS. The Schizophrenia Research Institute states that the current treatment methods do not cure schizophrenia; they only stabilize the condition to reduce the likelihood of psychotic symptoms returning.

Recommendation 6: Each case triaged should be assessed based on the consumer's individual situation and not by a 'one size fits all' scale. What may appear to be a psychotic episode for one consumer may be standard behaviour for another. Psychotic episodes don't always include violence and aggression.

Recommendation 7: The development of flexible service access for consumers. Being able to meet the consumer in a way that makes it possible for them removes the barriers that restrict severely unwell consumers receiving treatment.

Recommendation 8: Change in legislation to include carers in the decision to place a consumer in involuntary treatment or admission. Carers know their loved one well and can provide invaluable perspective to the service when the consumer has lost insight.

Thank you for opening up the opportunity for individuals like myself to share my experience, with the hope that together we can continue to keep making improvements in the delivery of mental health services in NSW.

Kind regards

Jennifer Allen