Submission No 477

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Name: Mr Phillipe Millard

Date Received: 18 January 2021

Inquiry into Health outcomes and access to health and hospital services in rural, regional and remote New South Wales

I *wish to advise that I put this submission to the iniquity and the information and comments herein form my personal story pertaining to the experiences relating to the hospitalisation and care of my disabled brother. My experiences are whilst acting as his appointed medical guardian and family member.*

Whilst I hold a background in nursing and position at the NSW Nurses & Midwives Association as the Recruitment Liaison Officer, this submission and the views I express in no way relate to my employer or my employment and therefor I wish to submit this document and any further information I may be called upon to supply, as a member of the public, concerned family member and my brother's appointed guardian and advocate.

I give consent to publishing this submission as my brothers appointed guardian and I would be happy to be called upon to provider further information to the inquiry committee in person, if required.

Terms of Reference

This submission is particularly in relation to the following terms of reference.

(a) health outcomes for people living in rural, regional and remote NSW;
(c) access to health and hospital services in rural, regional and remote NSW including service availability, barriers to access and quality of services;
(d) patient experience, wait-times and quality of care in rural, regional and remote NSW and how it compares to metropolitan NSW;

Submission

I Phillipe Millard lodge this submission to highlight the difficulties I had accessing and ensuring appropriate healthcare, diagnosis, treatment, referral and outcomes for my 47-year-old intellectually disabled brother Paul Vincent Millard in 2 rural hospitals within the Mid North Coast Local Health Distract. (MNCLHD).

It aims to point out the problems with accessing the best and most appropriate care when residing in country NSW and highlights inadequacies for people with disability regarding receiving the specialist care they need.

It also highlights problems when Local Health Districts (LHD's) refuse to refer on to other LHD's that have the specialist or skilled staff and appropriate In-patient unit with nurses to address complex needs.

It highlights how the issues of not referring a patient in a timely manner causes delay to appropriate treatment, additional and increased costs in treatment and can cause a chain of events that can be lifechanging for that individual and their family.

Overview

My brother Paul has a rare developmental disability, Fragile X type known as CUL4B. I am his appointed guardian including his medical guardian.

Paul lived in a group home in Kempsey NSW for around 20 years and is an NDIS participant. He has the mental capacity of a 4-6 year old and usually enjoys a pleasant and happy personality.

In February 2019 his health rapidly declined and his mood, behaviours and sleep patterns changed suddenly. New behaviours emerged including, swearing, yelling, spitting, bitting, kicking, hitting, banging things and throwing furniture.

At worst, he would bang his head against walls, sustaining injury. At times he would become incontinent or urine and faeces. He became increasingly aggressive towards care staff, clients and family. He became a risk of harm to himself and others.

Activities of Daily Living (ADL's) slipped and personal hygiene became difficult to manage.

In around 7 months he had 12 presentations/admissions to Kempsey District Hospital (KDH) & Port Macquarie Base Hospital (PMBH) since the 27 Feb 2019.

Most presentations resulted in a fast discharge back to the group home who were struggling to cope with the elevated behaviours and aggression.

Care staff were injured following discharges and some staff required time off work from their injuries.

On presentations to hospital it was difficult to get medical staff to listen to the concerns of myself and the group home and to get the care and support we so desperately sort.

On presentation with his escalating behaviours, medical staff wanted him discharged ASAP. Given the number of presentations, I had to continue to request he not be discharged.

Despite many concerns, a Doctor from KDH phoned the group home two days in a row and told them to come and get him. I had to request he stay admitted given he was a significant safety risk to himself and others.

Doctors then began exploring nursing home placement but this was clearly not a suitable option given his acute condition, age and disability and given the inadequate staffing in Aged Care.

In later admissions, Paul would require one nursing special per shift as well as a security officer present at all times.

I questioned if Paul might be in pain as I was advised he had arthritis in his spine. He was charted 1 gram of Paracetamol 3 times a day. I believe this was inadequate treatment for

pain in a rural hospital.

A Geriatrician reviewed Paul. He told me he thought Paul may be suffering from Frontal Lobe Dementia although they would not conduct tests to ascertain this diagnoses.

Tuesday 29 July 2019 a meeting was held at KDH with myself, the Medical Unit Physician, Psychiatrist and others.

It was clear that nobody wanted to take responsibility for Paul clinically. I was told he was not medical, they refused to believe he had Mental Health issues and although Frontal Lobe Dementia was queried, he was too young for Aged Care. He was ineligible for the Confused Older Persons Unit so there was no appropriate place for him in the Public Health System in NSW.

Paul had experienced a similar situation in 1999 and was sent to the Mater Newcastle, then on to James Fletcher and finally to Morrissett Hospital for successful specialist disability and mental health treatment.

I requested that he be transferred to Hunter New England LHD for further review and specialist care but was told Morrissett were not accepting new patients. Staff searched the State but there were no facilities able to take him.

Given this, I requested Paul be placed in the Mental Health Unit (MHU) at Port Macquarie given the following:
1) His past history and the amount of psychiatric medications he was taking as well as PRN meds.
2) His escalating behaviours and the unsuitable highly stimulated environment of the medical ward in KDH.
3) The large amounts of chemical sedation he was requiring on that ward
4) That I believed he was acutely unwell
5) That the local hospitals medical staff were clearly not skilled to cope with the situation.

The psychiatrist stated Paul was not suitable for the MHU in PMBH. I questioned how he felt he was more suited to the medical ward in Kempsey, occupying a room with a glass sliding door which he was slamming and a glass viewing window that he was hitting, across from the nurse's station with much activity and stimulation.

Paul was now requiring two security staff and a nurse special across 3 shifts per day. Nursing staff were not Mental Health trained and clearly unable to manage the increased behaviours that were escalating daily.

I felt Paul might be experiencing an acute mental health situation given he had a diagnosis (Dx) of schizophrenia in the past but doctors were adamant he didn't have a mental illness but could not say what the problem was.

I expressed concerns that someone needed to take on his care and that I felt things were going around in circles and we weren't getting anywhere.

I again asked if he could be transferred to another LHD such as Hunter New England as he had received specialist care there before at the Mater, James Fletcher and at Morrissett Hospital for long term recovery, with great success.

Finally a psychiatrist agreed to take him and announced to other clinicians, words to the effect: **"*I need to make it very clear, by no means let this set a precedence for Disability to be a dumping ground in our Mental Health Unit!*"** Referring to the Mental Health Unit (MHU) at PMBH.

I challenged this responding, "*We need to do something about this situation. Paul doesn't fit any of your boxes and that's the problem here!*"

Saturday 3 August 2019

Day 7 of this admission, Paul was transferred from KDH to PMBH (MHU) with further escalating behaviours**. He now required sedation and an anaesthetist escort via ambulance.**

3 days later a Psychiatrist phoned to say they would be discharging Paul the next day as he was fine. I questioned this as he had physically attacked me the day before.

Wednesday 7 August 2019

The next day I was advised Paul was experiencing an acute Benzodiazepine withdrawal. I expressed concerns saying, "*But you wanted to discharge him today?"* This proved he was still acute and in need of specialist care.

My brother was displaying signs of withdrawal when I saw him around day 3 of admission to KDH. He was extremely unwell and at one stage laid on the floor in front of the nurses station to try to communicate how sick he was but this was put down to "attention seeking behaviour".

I attended several meetings whilst he was in PMBH. I argued he was not well and very unsafe but there was always pressure in these meetings from the LHD executive to get Paul out of their MHU.

LHD staff and Doctors told me more than once that I was causing bed block in their Emergency Department and that my brother was taking up an acute bed and preventing others from accessing care.

During his admission, Paul developed a tooth ache and I was told they had no dentist on site and it was my responsibility to take him "down the street" to a dentist.

Paul was at risk of injury to himself and others. He could have attacked someone on the street or ran in front of a bus. He was unsafe to transport in my car and there was no way I could have left the hospital safely with him.

It's hard to believe a rural Base Hospital like Port Macquarie was unable to access a visiting dentist to rule out acute dental pain which may have been contributing to unexplained behaviours.

The psychiatrists admitted they didn't know what the problem was.
They told me I just needed to accept that this was my "new brother" but given the changes were so sudden, I felt it would have been neglectful of me as his brother, guardian and advocate to just accept this without pushing for further review.

PMBH then decided Paul needed a Neuro Psychiatry consult. The closest unit was Newcastle and part of HNE Health, only 2.5 hours away.

Again, I requested for Paul to be referred to HNE Health but **the response was that they didn't like to refer on to other LHD's.**

I resided in Newcastle and had to travel 5 hours in total a day to liaise with doctors and visit so was keen to see him referred to Newcastle.

MNCLHD then spoke of flying a Neuro Psychiatrist to PMBH from POW Randwick, Sydney but this couldn't be arranged so the consult we so desperately needed never happened and this would ultimately hamper Pauls recovery by around 9 months.

As there was no improvement, Paul's group home in Kempsey refused to take him back. Fortunately, a new NDIS Accommodation Provider was found in the Hunter area.

Paul was discharged to their care with very little improvement in behaviour and requiring 5 care staff per day to manage him in the community.

Arrangements were made for follow up with the Neuro Psychiatry Department at Randwick Hospital but this never happened as the appointment was difficult for me to obtain post discharge.

There was also the added issue of physically getting Paul to Sydney for the appointment. Frustrating that PMBH couldn't have accessed HNE Health which was closer and more accessible.

In March 2020 Paul became physically unwell and was so exhausted by the constant uncontrolled behaviours and lack of sleep. He had lost a lot of weight and was admitted to the Mater Newcastle. I felt my brother only had a few months to live as he was in such poor condition.

Medical Staff were shocked by his ongoing uncontrolled behaviours and after a medical work up was then admitted to the Mater Acute Mental Health Unit for further assessment.

He was then transferred to Morrissett Hospital under the care of the Neuro Psychiatry Team where a total assessment and medication review took place as an in-patient.

He was discharged around 6 weeks later and due to the treatment and medication changes, we began to see significant improvements in his mental and physical health.

Much of the agitation and aggression has gone and Paul has started to take an interest in life again. The Neuro Psychiatrist reported a deep clinical depression combined with a serious mood disorder and prescribed medications that have been life changing for my brother and significantly improved his quality of life.

He is now sleeping well again and has started to take up some of his previous activities like tenpin bowling and swimming. He is venturing out into the community again and enjoys socialising with others.

The multiple admissions and lack of diagnosis at both KDH and PMBH and their reluctance to transfer Paul, caused him to lose his accommodation in his group home in Kempsey where he had resided all his life and was well known in his community. It almost saw him placed in Aged Care which would have been a disaster.

I submit this in the hope that no other family will suffer such poor standards of access to healthcare, especially persons with disability who often cannot communicate and advocate for themselves.

Country people deserve better with it comes to their health and people need to be referred on where there is not the specialist care available in rural NSW.

I believe if I had not been such a strong advocate for my brother, the situation may have been much worse and he would have died. I hold concerns for anyone trying to navigate a system that focuses more on its budget, than its people.

I welcome this inquiry into health outcomes and access to health and hospital services in rural, regional and remote NSW and thank you for the opportunity to provide this submission.