

Submission to the Productivity Commission 2019 Inquiry into Mental Health

Our story is book-ended by tragedy. It is the story of my brother P and begins with an episode that marked half a lifetime of lost potential and illness, culminating in his early death at 37.

At 18 years of age, at the beginning of his first year of university, P suffered his first bout of psychosis. He was subsequently hospitalised and diagnosed with paranoid schizophrenia. The episode remains vivid for us as he attempted (unsuccessfully) to burn the family home down with my mother and me inside. He had then, when discovered, locked himself in his bedroom for 3 days, wailing or silent, with my parents and me too frightened to force entry into the room but equally appalled and traumatised at his obvious pain and suffering.

My parents rang the CAT team (emergency psychiatric community team) and, after a lengthy delay due to the CAT team waiting for the police to be available to attend, the CAT team and police eventually arrived and my brother was subsequently hospitalised. This was the first of many hospitalisations for him and the last of any significant study or long period of work.

One of the extremely frustrating features of this first hospitalisation was the refusal of the medical staff to discuss P's condition and treatment with our parents, on the basis that he was 18 years of age. This meant that, until our mother finally convinced the psychiatrist treating P that there was information about his birth and early life which was important for them to know, the treating team was relying on P for its information, who was in a state of severe psychosis.

Aside from the inherent challenges he faced, living with a complex mental health disorder, P was beset, for the remaining 19 years of his life, with a cascade of issues, flowing from and exacerbating his mental ill health. These included housing, continuity of care, community support issues, drug and alcohol abuse and loss of social capital.

Housing

After his first major episode of mental ill health, it was agreed by both our family and the doctors treating him that P could not return to live in the family home. Thus began our experience of the inadequate and under-resourced social housing sector. He went onto the public housing waiting list and did eventually get a unit, 17 years later. In the intervening time he lived in various rooming houses, hostels and units run by a variety of programs for people with mental health issues. Much of this time, although he had a roof over his head, he was surrounded by people with like mental health and drug issues. As a result, he lived in high stress environments which carried with them significant risk factors in terms of exposure to drugs. Additionally, he would often lose his accommodation when he was readmitted to hospital, so the housing search would need to resume after most hospital admissions. His sense of place and belonging would also be uprooted each and every time he experienced a deterioration of his mental health/hospital admission.

Our parents contemplated buying a unit for my brother to live in, but initially could not manage this financially. By the time they had the financial means to do so, the tense and volatile relationship with my brother made this impossible to advance. P would oscillate between complaining that his family was doing nothing to help him and rejecting any involvement of his family in his life. As a result, our parents had little confidence that the purchase of housing for P would in fact resolve his housing instability.

My brother did eventually get a public housing flat, and it did bring him a sense of place and stability for a time. However, ultimately it came at great cost: in order to secure this housing option my brother had to move to a different geographical area with different mental health services and providers. We believe that this move was one of the key factors leading to his untimely death.

Continuity of Care and Community Support

For most of his life post-diagnosis, my brother lived in the Alfred Health region. His illness did, from time to time, create tensions in his relationships with those caring for him, both in hospital and in the community. However, on the whole the outreach team at Junction Clinic and later at Alma Road provided continuity of care and built relationships which facilitated his engagement with the available community support options. During the last year of his residence in the Alfred Health area, he was part of the 'New Horizons' program which provided intensive support through a multi-disciplinary team. He responded well to this support and we were all hopeful for his future. However, his housing tenure remained uncertain, so when he received an offer of a public housing flat within the Eastern Health region, it seemed too good an offer to pass up.

The down-side of accepting the security of tenure was that it necessitated a move away from the Alfred Health region and its New Horizons program, with its known and trusted care-givers and its intensive level of support. There was no equivalent program in the Eastern Health region and he found it difficult to adjust to the loss of access to the community support workers he felt he could trust. The limited community support available to him in the Eastern Health region was exacerbated by frequent changes in personnel, making it even more difficult for him to develop a sense of trust in those delivering his care. Not surprisingly, then, my brother's mental health deteriorated and in November 2015 he was again hospitalised.

For much of the 7 months of this hospitalisation, my brother was in the High Dependency Unit of Upton House, Box Hill Hospital and at times was held in isolation. In May 2016, my parents participated in a roundtable meeting with staff from Upton House (including the consultant psychiatrist, the psychiatric registrar, psychiatric nurse, occupational therapist, social worker), as well as people we understood to be Eastern Health staff responsible for co-ordinating referrals to ongoing support programs. At this meeting, the clinicians emphasised strongly, repeatedly and unanimously that my brother needed to be discharged to a transition program, such as a rehabilitation facility "when a bed became available" and NOT directly to his flat. Despite this, less than 4 weeks later, my brother was discharged to his public housing flat. His only ongoing care comprised two short appointments per week which he was required to attend at the Koonung Community Mental Health services office for medications. Apparently, the potential transition services had refused to take him because he was deemed too high a risk (we believe based on violence displayed towards a doctor during a hospitalisation 7 years earlier).

The week before his ultimate discharge from hospital, we raised the following concerns with P's in-patient mental health team:

- That he would not receive the rehabilitation program which the case team had indicated was absolutely necessary for someone exiting hospital after 7 months of intensive treatment;

- That the level of care he would receive from the MST team would (in our opinion) not be adequate;
- That my parents were leaving for more than 3 weeks overseas (for my mother's work) and would therefore not be available to support my brother in this transition;
- That my other brother was living in Budapest, Hungary and was therefore not around to help;
- That I was working and had 3 small children, so would have limited capacity to support him;

That he had a long history of intermittent drug use (he was not addicted but used drugs periodically to self-medicate), yet he was not being immediately linked in to drug and alcohol support programs. Despite the family having raised these concerns with the treatment team, the form MHA 111 (Variation of Temporary Treatment Order or Treatment Order) completed on 14th June 2016 (the day before his discharge) and converting my brother's In-patient Treatment Order to a Community Treatment Order noted "No immediate and acute risks". We canvassed these issues with Eastern Health following P's death and have met with them on two occasions to discuss our complaint.

Given our concerns, I agreed to visit my brother at least once per week, and we arranged for him to have email and/or sms contact with our parents and our brother and regular phone contact with me (which he did). On 28th June 2016, just 2 weeks after his discharge, I was unable to contact him. Next morning, I contacted the Eastern Health MST team and was told that my brother's Case Manager had gone on leave (no family member had been informed of this), but the back-up Case Manager confirmed that my brother had attended his appointment on the 28th. I expressed concern about the lack of support he was receiving and about his social isolation citing multiple conversations I had with him where he eluded to a sense of hopelessness about assuming life roles/work/activities in the community. The MST team and I both agreed to keep trying to contact my brother. That night I left a message on the MST team answering service to say that I had still had no luck getting in contact with my brother (and that this sudden cessation of contact was out of character for him at that time).

Next morning (30th) I had further phone contact with the MST team and a police 'welfare check' was arranged (with me present) for that evening, though as I had no key to his flat, they were unable to check inside. The food I had left on the Tuesday was still where I had left it and no lights were on in the flat. In response to my expressing great concern, the police suggested I try to obtain a spare key to his flat and wait to see if he arrived at his scheduled MST appointment on Friday at 2pm.

On Friday 1st July I heard from yet another (different) MST Case Manager that my brother had not attended his scheduled appointment with the MST team. MST then co-ordinated another welfare check involving Box Hill police, this time with me having collected the spare key to my brother's flat from my parents' place. When the police and I entered my brother's flat, we found him dead on his couch, apparently from an accidental drug overdose.

While the care my brother received over 7 months as an in-patient at Upton House was excellent, his discharge planning and implementation was (in our view) far from adequate. In particular:

1. the failure to provide the transitional program which had been highlighted by the treating team as absolutely necessary for my brother was (we believe) a major factor in his death;
2. the totally inadequate support provided to him following his discharge and the constant switching from one Case Manager to another compounded this.

Liaison with drug and alcohol services

As noted above, despite the fact that my brother had a long history of intermittent drug use, little apparent effort was made at the time of his discharge to link him in to a drug and alcohol support program. The morning after the police and I found my brother's body in his flat, I received a phone call from a Case Manager at Eastern Health MST, asking how the welfare check went. When I informed her that he had been found dead, apparently from a drug overdose, she expressed shock and told me that the team had not thought he was at any risk of drug abuse. While she was very supportive in her conversation with me, we felt that her comment displayed an incredible level of naivety on the part of the MST service given his history. He had previously been linked in with drug and alcohol support services through Alfred Health.

Social capital

Evidence over recent years indicates that social capital (social connectedness demonstrated through strong relationships, high levels of trust, norms of reciprocity) is linked to positive health outcomesⁱ. My brother grew up in a family with high social capital and it was evident in his life prior to the onset of his illness: he had a network of friends; he coached a junior cricket team and played cricket himself; he participated actively in family and broader social events. However, with the onset of schizophrenia, he became socially isolated, became distrustful of others (including health professionals) and withdrew from social interaction. Although his capacity and willingness to participate socially varied over the years of his illness, our feeling is that the paranoia associated with his illness constantly undermined his capacity to trust and relate to others.

In such a situation, the building and maintenance of trusting relationships with care givers is both more difficult and more essential. In my view (and the view of my family), the disjunction between services offered in different health regions and particularly the differences in the levels of out-patient care offered in the two different health networks in which my brother received the majority of his care, played an important role in the deterioration of his mental health over the last 2 years of his life and ultimately in his death.

ⁱ Berry, H.L. & Welsh, J.A. (2010), 'Social capital and health in Australia: An overview from the household, income and labour dynamics in Australia survey', *Social Science & Medicine* 70: 588-596