

I am a consultant currently working in the area of disability. However, this submission is through the lens of personal experience in advocating for my brother D who lived with schizophrenia. I will start with D's story and then move to the draft report and areas of concern.

I have serious concerns regarding the treatment of D. On 15th July 2019 I rang the police to do a welfare check on D, who lived interstate, as I had been unable to contact him by phone. D had an aversion to using the phone due to his mental illness and his lack of contact was not unusual. As well, for approximately 35 years D received significant support, including in home support, and I believed I would be contacted if there were concerns. At 10pm that evening two police knocked on my door to inform me that D was found deceased in his home, and had been deceased for approximately two months. An autopsy could not be performed due to the length of time between his death and the discovery of his body. I cannot convey the distress this news caused me and I am bewildered that a person with a mental illness and high needs, who had been receiving a range of services, could be dead for two months without the knowledge of any of his service providers.

In the six months since my brother's death I have contacted each organisation and person involved with D and obtained a verbal or written account of what they believed occurred; applied for and received a copy of his medical reports and National Disability Insurance Scheme (NDIS) plans; obtained and read police statements; sought information from various departments and government ministers and obtained information from the Coroner including the autopsy report, in an attempt to piece together what happened. At this stage it appears that each organisation followed policy, which indicates there are significant issues with policy if a client with high needs can die with service providers completely unaware that this

has occurred. There were three key problems that led to the two month delay in discovering D's body:

1. The poor interface between mental health services and the NDIS.
2. Fragmented service delivery.
3. A lack of case management and care coordination.

The above problems stem from economic rationalism through the use of market philosophies and business sector practices in the delivery of government funded services. In this approach, there is a misguided belief that the government can improve service quality through competition. My brother's untimely death has implications for the delivery of mental health and NDIS services. My aim in sharing D's story and commenting on the report is to prevent the untimely death of others living with mental illness. I will now highlight two areas of the report that have significance in my brother's situation.

Firstly, the premise of the report is to improve '*mental health to support economic participation and enhancing productivity and economic growth*' (p. iii Issues Paper). The notion of '*enhancing productivity and economic growth*' is a neoliberal philosophy based on the rhetoric that citizens can achieve greater independence and economic self-sufficiency by incentivising paid labour. There is much that is problematic in an approach that extols economic independence and sees dependence as a denigration of the person. In New Zealand, well-being rather than economic growth is the indicator of success and it has recently implemented a progressive, equity based, approach to mental illness focussing on valuing people rather than money.

The neoliberal approach created problems for D as he was significantly disabled by his mental illness, and other disabilities, and was unable to financially contribute to society in any way. Despite this, D's last NDIS plan in 2018 contained the following goal:

'I would like to be supported with my employment where I work.'

This goal did not originate from my brother, as he had resigned from his position in a supported employment organisation and felt that he was physically and mentally not able to return to work. The emphasis on employment created barriers with the support coordinator who focussed on a return to employment. Hence, the NDIS plan did not stem from my brother's needs and he lacked choice and control in the delivery of his supports.

Within each society there will always be people unable to work and they should be valued for who they are, regardless of their participation in paid work. The report states there is *'significant stigma and discrimination around mental ill-health, particularly compared with physical illness'*, yet the underlying premise of the report, that of productivity and economic growth, leads to stigmatisation. However, I do applaud the recommendation of a National Stigma Reduction Strategy (p. 807) and I hope the needs of those with mental illness who are unable to work receives attention.

Secondly, I would like to discuss care coordination. The following quote is from page 335:

Coordination is a form of integration, which refers to different entities or providers working together to ensure that a consumer receives all the different types of care they need in an organised and efficient manner. There are different models of care coordination — some may involve only referrals and exchanges of information between clinicians, while in other cases a dedicated coordinator or a care team help the consumer to navigate the mental health system and connect them with all the supports they require (PC 2017b; WA DoH 2019).

D had case management from his mental health team for approximately 35 years, but was discharged from this program to be cared for by his GP in 2018. Under this model his mental health services were not replaced. This is unacceptable. D was provided with a support coordinator through his NDIS funding, but this did not include

case management, a '*care team*' and nor was there any linkage with mental health services. D did not have support to '*navigate the mental health system*' and he certainly did not have the supports he required.

D saw a community based GP and required regular injections, yet when he did not turn up for his injection, there was no follow up because D was a voluntary patient. I believe the recommendation in the report for improved support for GPs is a positive move, but this must be linked to a co-ordinator who can follow up patients who fail to turn up for appointments. In my brother's case, this could have made a difference. D's services were fragmented and disjointed, he did not have a clear pathway for care. People with severe and lifelong mental illness require comprehensive case management from staff who have an understanding of the fluctuating nature of mental illness. The report discusses '*care coordinators*' who would '*work directly with the consumers, their carers, clinicians (or clinical coordinator) and providers from other sectors, to establish the types of services needed and provide assistance in accessing and coordinating those services*'. This is a positive move. I strongly recommend that care coordinators acquire a deep knowledge of mental illness and ongoing training. I also believe that continuity of care would have made a difference for my brother.

Thank you for the opportunity to participate in this important review, and I welcome the opportunity for further dialogue.