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## SUBMISSION TO THE PRODUCTIVITY COMMISSION

### INQUIRY INTO MENTAL HEALTH

April 2019

My submission to this Inquiry is in part a reflection of my experiences of caring for my son as he struggled with mental illness through adolescence and early adulthood until his death on 24 December 2009, aged 28, and in part a response to the Issues Paper based on my current knowledge and experience of the mental health system as a carer representative at the Brisbane North PHN and member of the Peer Participation in Mental Health (PPIMS) network.

I note that the scope of the Inquiry includes examining “what Australia is losing” (p. 4) due to mental illness across the community. Reading that, I reflected: *Well, I lost my son; my daughter lost her only brother; and I lost the most productive years of adult life* (so that I became dependent on welfare). I’m not sure what Australia lost, exactly, but I do know that a good person was allowed to die due to the failings of the mental health system, especially the mental health system in Queensland in the early 2000s.

What does “allowed to die” mean? It means that “the system” failed him, as it does so many other young people. My purpose in writing this submission is to point to some of those failings and the reasons for them. At the basis is the disconnect between systems and people: individuals don’t usually conform to patterns devised by others, and this is especially true of mental illness which is generally episodic in nature. Somehow, systems have to recognize the individuals in it, develop a sense of humanity, and speak the truth.

I acknowledge that there have been a number of changes, innovations and improvements in the mental health system since 2009 (actually dating from around that time in some instances), especially at the Federal level. For example, the establishment of the Medicare Locals (subsequently PHNs) and Partners in Recovery; a greater recognition of the need to reach out to diverse groups; Stepped Care; and better collaboration and partnerships between federal, state and non-government organizations. At the same time, the Recovery Model is generally accepted as the best framework for delivering mental health services, and there is also much greater awareness of the importance of work as a path to a contributing life.

In relation to Queensland, glaring gaps and inconsistencies in the mental health system that have been overlooked in the reform process have recently been identified: first, in Brisbane North PHN’s Regional Plan, [Planning for Wellbeing](#), and second, in the Queensland Mental Health Commission’s Strategic Plan, [Shifting Minds](#). Both papers were developed via robust community consultation and both point to the poverty gap between families and individuals coping with mental illness and the rest of Australia. In reference to the Strategic Plan, I note in particular their Focus Area 1, which includes “removing barriers to social and economic participation” (p. 21); similarly, the Regional Plan notes that social and economic isolation is a serious factor negatively impacting on people living with severe and complex illness in the community.

Poverty, social isolation, disadvantage, stigma ... these things have not changed very much, if at all, since I was looking after my son in the early 2000s—when I was pleading with clinicians to monitor him more carefully; begging for more compatible case managers; at times giving up my home (at great expense to me) so that we (i.e., my daughter and I) knew he would be safe; keeping him safe; helping him find a place to live; trying to keep my daughter safe as my pleas (again) to Queensland Health (again) that we needed more help because she was growing up in an unsafe environment fell on deaf ears (again) ... the list is endless. And, as it turned out, our efforts were in vain because my son died anyway.

## AREAS OF CONCERN

In relation to the Issues Paper, I have identified the following areas of concern—or needs—that must be addressed in this Inquiry, namely:

- The need to address the poverty associated with mental ill health that impacts individuals and families through generations (economic and social participation);
- The need for more and better housing options (housing); and
- The needs of carers and families (economic and social participation).

### 1. Poverty

The impact of mental illness on my family was, and continues to be, enormous. My son was not able to complete his university studies, and he could not keep a job because his mental illness caused problems in the workplace.

- There needs to be much greater support for people with mental illness to study or find obtain work and to be supported in their work and study. I envisage a system where large employers (and colleges and universities) having policies in place to support people living with a mental illness just as there are enabling policies for people living with a physical disability. That would be a real level playing field.

At the same time, my daughter suffers from anxiety, has been unable to complete tertiary study, and finds it very hard to maintain full-time employment. The detrimental economic effects of her brother's mental illness will be with her for a lifetime.

- There is no option at Centrelink (for example) to make allowances for people in her situation, so that she might work a little and study a little, and be properly supported. (Currently, the rules stipulate two or three units as part-time study, to qualify for Austudy, which is too much for people when they are unwell. And the cut-offs for income before payments are reduced are too harsh, so that you can never get ahead.)

Equally, when my son was unwell, I was only able to work part-time (at that time, as a university lecturer and tutor in linguistics), and due to the financial stress I was under (and continue to be), I have not been able to complete my PhD. And since his death, I've had to leave the academic life and find other ways to make a living, dealing with grief at the same time. Again with reference to the Issues Paper, while I agree with the statement that “social participation and inclusion are inextricably linked with mental health and wellbeing” (p. 28) it is wrong to assume that people with mental ill-health merely need opportunities (merely) to

“acquire skills” (p. 31), when many people living with mental illness are highly intelligent and possibly well-qualified in a particular field.

- A year or so ago I noted on social media that the Queensland Government was sponsoring a Certificate II in Hospitality for people with mental illness. I consider that condescending and stigmatizing in the extreme. Why not a Certificate IV? Or a TAFE course? Or a university degree?

## **2. Housing**

When my son died, he was living in community housing in Kelvin Grove. He had been there less than a year. Before that, he moved from place to place, with no one or no agency seemingly able to help him. If it were not for my frequent interventions, he would have been on the streets.

- It is not too difficult to build low-cost housing—not for international students (the system seems to be biased towards this easy and lucrative-to-developers type of accommodation) but for low-income people here in Australia forced to live in private rental accommodation where more than half their weekly income goes to pay the rent. (One definition of poverty is housing costs higher than 30% of weekly income, and even that is close to the threshold of income stress.) Waiting lists for public housing are far too long and the system is discriminatory—if you get to the top of the list and you are offered something not suitable to your needs, then you go back to the bottom.

## **3. Families and Carers**

The changes in the mental health system I noted above have done little or nothing to improve the lives of families and carers. The issues I faced 10–15 years ago seem to be the same now. For example, the assumption that the hospitals can always rely on carers to pick up the slack due to the states’ own inadequacies. This means that carers constantly live in a highly stressful and sometimes dangerous environment.

- The issue of safety is overlooked and ignored.
- On one occasion I was “bullied” by a hospital consultant to take my son home when he was clearly not well enough to come home. The result was a smashed window costing hundreds of dollars in emergency repairs, his re-admission to hospital, and subsequently, the housing problem described above.
- Families and carers live in poverty or semi-poverty.
- Families and carers have mental health issues of their own as a result of having to care for a family member beyond what is reasonable in a health system that can offer the best for, e.g., cancer treatment.
- The demands on families and carers are, basically, intolerable.

## **CONCLUSION**

In this Submission to the Productivity Commission I have identified a few areas of concern with examples to support my case, and made a few suggestions where specific changes need

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to be made. My response to the Issues Paper is based on my own perspective, knowledge and experiences; nevertheless, I believe they are valuable, and I hope what I have written here will be taken on board and contribute to improving the way governments and organizations and systems address the needs of the countless individuals who are lost, year by year.