

# Productivity Commission – Mental Health Inquiry 2019

## Submission from a mental health carer

This submission raises three economic questions surrounding present public policies related to mental health carers. For purposes of discussion of these questions, its focus is on carers of people who suffer from what are often termed “severe and persistent” mental illnesses. That is, carers of loved ones who suffer from schizophrenia, bipolar disorder, and the like, rather than carers involved with, say, the more common mood disorders of limited or finite duration.

Also, the discussion does not go into detailed analysis (I’m just your average mental health carer), but hopefully is sufficiently intriguing for the Commission to be moved to investigate further.

### **1 – Economic value of raising the capacity of mental health carers**

In recent years, some studies have estimated gross dollar values represented by Australia’s band of unpaid mental health carers. These have tended to concentrate on the cost to the state if it were to take over this task. For example, the overall value to the state of mental health carers has been shown to be an astounding \$13.2 billion. This being the estimated cost to replace informal mental health carers with formal services<sup>1</sup>. Key messages from the study were:

1. An estimated 240,000 Australians care for an adult with mental illness.
2. Mental health carers provide large amounts of unpaid support, often on a fluctuating basis.
3. Most mental health carers’ time is spent on emotional support.
4. Mental health caring differs from other types of caring.
5. It would cost \$13.2 billion to replace informal mental health care with formal support services.
6. Conservatively, \$1.2 billion is currently spent on support for mental health carers.
7. Not all carers are accessing support services or feel their needs are being addressed.

The primary message here is that mental health carers represent an extraordinary resource. And it logically follows that mental health services (and thus the wider community) could benefit from harnessing these informal carers and investing in raising their capacity. I am frustrated that, despite ample international evidence, there has been little in the way of specific Australian economic studies investigating this potential and thus influencing public policy and investment.

Here are some simplistic numbers which point towards this untapped potential. Suppose a notional ‘typical’ consumer has 10 days hospitalisation each year and in addition has fortnightly community ‘case management’ contacts of about an hour on each occasion. The mental health service cares for 266 hours per annum, family and carers do the other 8,494 hours – a ratio of 32:1. Such arbitrary numbers are acknowledged as fuzzy – there is an imbalance of skills apart from anything else – but the implications are clear.

However, no one seems to be asking the question: ‘What if we raised the capacity of these carers?’ It’s true that the notion of there being some sort of state obligation to better care for carers has been recognised in recent decades. For example, NSW launched its NSW Family & Carer Mental Health Program back in 2005. But this was more based on it being ‘a good thing’. In today’s economic climate, there is a real need to investigate the return on investment of taking a further

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<sup>1</sup> Dominic S et al; *The economic value of informal mental health caring in Australia: Summary Report*; Mind Australia, March 2017

deliberately structured step of raising the capabilities of carers. That is, we need to answer the question: What would it cost to make carers X percent more effective, and what savings in hospital-based acute care would result? My simple arithmetic says this is a better investment of public funds than Badgery's Creek Airport, but I'll leave further exploration of this potential to the Productivity Commission's vastly superior capacity in research and economic modelling

To conclude this first topic, I want to mention the proven beneficial effects of the evidence-based therapeutic intervention generally known as psychoeducation. That is, education which aims at improving knowledge of mental illness, of its symptoms and of the (baroque and disjointed) mental health 'system'. At the same time, psychoeducation typically sets out to enhance personal skills such as communication, resilience, stress management, plus social and emotional skills generally.

Significant benefits are shown to accrue when there are structured programs of psychoeducation both for patients and for family and carers. The literature is now extensive in relation to illnesses involving psychosis, and it consistently reports positive benefits for the consumer, together with reduced costs for mental health services.

For example, a year-long Italian study<sup>2</sup> involving 150 patients over 15 centres with schizophrenia demonstrated improved relapse rates, shorter hospitalisation, and improvement on most clinical parameters and on quality of life for the consumer. The authors note that even short term educational-informative contents were able to improve the patients' level of compliance to the treatment program, the patients' and their family members' attitude toward the disorder, and their attitude toward the psychiatric staff.

Some studies note that family carers particularly valued a group format for psychoeducation<sup>3</sup> which enabled them to share experiences with other carers, plus skilful facilitation by professionals, and knowledge and skill development.

Interestingly, there is a growing literature showing family psychoeducation reducing relapse in major depression. One study for example<sup>4</sup> showed patients whose families received information and problem-solving education to reduce stressful family interactions had lower relapse rates at nine months.

United States studies demonstrate specific savings in hospital costs derived from improving relapse rates. For example,<sup>5</sup> in New York, for every \$1 in costs for family psychoeducation provided in a multifamily group format, a \$34 savings in hospital costs occurred during the second year of treatment. In a hospital setting in Maine, an average net savings occurred of \$4,300 per consumer each year over 2 years. Ratios of \$1 spent for this service to \$10 in saved hospitalisation costs were routinely achieved.

To its credit, the NSW Family & Carer Mental Health Program at times includes a few elements of simple psychoeducation, but there is a real need to develop a more structured approach based on economic studies of efficacy and on rates of return on investment of public funds.

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<sup>2</sup> Aguglia E; Pascolo-Fabrici E; Bertossi F; Bassi M; *Psychoeducational intervention and prevention of relapse among schizophrenic disorders*; Clin Pract Epidemiol Mental Health 2007; 3: 7

<sup>3</sup> Sin J, et al. *Psychoeducational interventions for family members of people with schizophrenia: a mixed method systematic review*; J Clin Psychiatry. 2013

<sup>4</sup> Shimazu K et al. *Family psychoeducation for major depression: Randomised controlled trial*. Br J Psychiatry 2011 May; 198:385

<sup>5</sup> McFarlane, W. R., Dixon, L., Lukens, E., & Lucksted, A. (2003). *Family psychoeducation and schizophrenia: A review of the literature*. Journal of Marital and Family Therapy, 29(2), 223-245.

## **2 – The plan to fold Mental Health Carer Respite into the NDIS**

One ongoing mess in mental health has been made inevitable by the institutional confusion of public health arising from the unnecessary gulf between state and federal administrations. Although the Constitution gives the Commonwealth no responsibility for public health, there are arguments from the federal sphere about the desirability of national systems. I don't take issue with the merit of this viewpoint, but what we have now is neither fish nor fowl. Bizarrely, we have an unnecessary and disastrous split between primary care (federal) and acute care (states). There is much rhetoric about coordinating committees and the like attempting to bridge this awful gap and bring about some imagined seamless harmony, but the reality on the ground for confused citizens is starkly different.

Perhaps nowhere is this more evident than in mental health carer respite. For reasons that are entirely unclear, the existing federally-funded Mental Health Carer Respite Program is being folded into the National Disability Insurance Scheme (NDIS). I'm sorry, but this is beyond absurd. Carers in fact have become quite worried about the Commonwealth mental health carer respite scheme disappearing entirely when it enters the abyss of the NDIS.

For a start, the NDIS was crafted with little or no regard for mental health disabilities, and carers have had to become accustomed to tying themselves into knots adapting existing NDIS processes and forms in order to access services for their loved ones. For example, as for disabilities which seem too mysterious for NDIS to cope with such as dystonia, mental health carers have had to learn what I've heard called 'the magic words'. Fill the form in with this word – failure. But use that word, and your application succeeds. Amazing. Hence concern about the carer respite scheme suffering a similar fate. Although I am aware that there has been a belated recognition of the shortcomings of NDIS in relation to psychosocial disabilities, it would seem even less able to deal with respite.

But the absurdity I've mentioned lies in the fact that NSW, for example, already has its Family and Carer Mental Health Program, which in many regions already provides short-term respite by way of outings, carer lunches and the like. Why is the Commonwealth not simply transferring its mental health carer respite funds to the states to augment already existing and successful carer support programs? Stroke of a pen, you'd think. And a whole lot less administration for NDIS.

## **3 – The economic downside of outsourcing**

Outsourcing of public services has been hugely fashionable in recent decades, though is now widely perceived – including within the ranks of government I understand – as having failed. Sadly, the process shows no signs of being rationalised through employing some 'horses for courses' logic.

In the instance of mental health carer support programs, it appears that decisions to outsource, where not simply based upon fashion, have been often based on a simplistic analysis of costs, with scant regard for outcomes or for economic efficiency. In some cases, there have been dubious assertions that carer support is not considered to be so-called 'core business'. I would submit that such assertions may turn out to be non-strategic – and, ultimately, sub-optimal.

When studying systems analysis many moons ago, I ran across the statement that: "It is possible to optimise all the several parts of a business while the whole is going bankrupt." Regrettably, I do not have the reference, but have seen this in action many times. It particularly occurs where expenses in one balance sheet give rise to income (or savings) in another. The operator of the first balance sheet sees no value in incurring such expenses. (Roads and railways being an outstanding example.)

I would submit that sub-optimal results of outsourced mental health carer support programs are arising from several factors. For a start, it is an axiom of institutional design that if you create a boundary, you create ongoing transaction costs. In carer support this can involve complex and costly bidding and ongoing contract administration, elaborate systems of data reporting, creation of otherwise unneeded management functions, and a too often poor translation of purpose and method from principal to contractor.

An observed issue for outsourced carer support is that the contractors may achieve only a relatively limited outreach into the mental health carer population. This, in my opinion, is primarily because they are separate from mental health care providers, both public and private, and thus lack ready access to comprehensive information on potential carers in need. This is, of course, not an insurmountable problem, but nonetheless is illustrative of issues resulting from institutional boundary creation.

But, more importantly, a significant problem perceived and voiced by carers is that contractor staff are too often junior and inexperienced. This arises directly from observed high rates of staff turnover, almost certainly brought about by short outsourcing contract periods. These periods can be as short as twelve months, which completely obviates any hope of attracting experienced applicants for vacancies. Even when contracts are extended to three years, the results are not encouraging. Carer observation is that support workers often seem to view such contractors as merely career stepping stones to more viable positions. The most complained about downside of this high turnover is that carers can find it difficult to build any constructive relationship with the support workers because of lack of continuity. In other words, the quality of carer support service is not what it could be.

This is in strong contrast to a situation where support workers/ clinicians are directly employed by a public health system. Compared to the average community-managed organisations or private sector providers, career progression becomes possible, and vital mentoring by senior staff is routinely available. (Relative size of organisation is also a factor.) Outsourcing may well appear as a reduction in direct operating expenses, but it too often delivers poor results when the actual outcomes and quality are properly examined. We can do better with our taxes.

None of this is to decry mental health carer support and capacity building. I and my family have received significant benefits from such programs and are grateful for them. But the overuse of outsourcing means that quality can be sub-optimal, and poor value for money. In addition, public health services miss out on the opportunity to reap the documented financial and patient wellbeing benefits which can flow on from closely-targeted carer capacity building. And, unfortunately, these major public services also do not receive any of the multitude of tangible and intangible flow-on benefits of having within their ranks a cohort of senior and experienced carer support workers.

Bottom line: Outsourcing has its place, but only when a business case includes comprehensive economic studies showing that there are real benefits beyond simple financial accounting.

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