Submission to Productivity Commission 2019

The role of improving mental health to support economic participation and enhancing activity and economic growth

Main Topics to be covered:
1. Housing and Homelessness.
2. Prevention and early intervention
3. Issues related to users of mental health services and supports
4. Issues related to carers, family and friends[1],
5. National Disability Insurance Scheme (NDIS).

Case Study: Story of two Davids

Homeless		Homeless
31 year old	• **28 January 2012** • **David Tsernick presented at Alfred Emergency Department saying he felt (psychiatrically) unwell,** • **Turned away because assessed as being not sufficiently unwell,**	**31 year old**
David Tserniak	• **Refused to leave, demanding help** • **Police were called – our health services could offer only the police to a person asking for psychiatric help**	**David Bryan**
	• **Police drove him to two shelters, none of which had room,** • **Police dropped him at corner of Grey and Jackson Streets St. Kilda** • **Two hours later, he was dead – stabbed to death on the sidewalk by David Bryan**	**Initially charged with Tserniak's murder, later reduced to manslaughter** ,

The above case illustrates some reasons why many individuals with mental health challenges are prevented from economic participation in society:

• homelessness,

• lack of community mental health facilities. For example – despite David Tserniak's insight into his need for help, the psychiatric unit he knew turned him away because he was not 'sufficiently unwell' for the acute hospital care that they offered. However, they had nowhere to refer him for

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[1] The term 'carers' will be used throughout to include all unpaid carers, whether related, 'family of choice' or friends who are Devoted to the individuals with psychosocial disabilities.

appropriate care and their only recourse was to call the police, who couldn't even find him a place to stay for the night ,[2]

The lack of appropriate facilities has not changed. 'Not sick enough' is a widespread response by mental health providers to a plea for help.[3] As with members of Inner South Family and Friends (ISFAF) who are regularly faced with the problem of their loved one being turned away from the emergency department of a psychiatric unit in a major hospital, such refusal invariably results in deterioration to crisis point of the unfortunate individual, prolonged hospitalization, increased (expensive) medication and reduced long-term ability to contribute to society. The cost of such lack of appropriate care, both in emotional trauma to all concerned and immediate and long-term financial cost of caring for the unfortunate person is an immense community cost which could readily have been avoided by the availability of suitable community facilities. Were suitable facilities available, the loss of productivity of the consumer and their carers would also be prevented.

- lack of drug and alcohol treatment, a poor penal system, readily available illegal drugs, an 'ice' (crystal methamphetamine) epidemic. As an example, the killer, David Bryan was able to kill David Tserniak despite having previously stabbed a random person multiple times in Queensland while on 'ice', served a three year sentence and been released from jail with the same drug addiction that he had entered with. His continued addiction and the availability of ice enabled him to repeat his earlier behaviour, by stabbing David Tserniak 12 times.[4]

Mentally unwell individuals cost society billions of dollars via very poorly designed mental health 'care' and support systems, causing vast billions to be spent on medication, much of which could be avoided had prevention and early intervention been available.

Carers, family ('family of choice') and friends assist when they can, thus they are also prevented from reaching their potential for economic and social participation.

1. Housing and Homelessness

In 2016, almost 10,000 Victorians under 25 years old were either homeless or in unstable accommodation.[5] Among a sample of homeless individuals in Melbourne, 31% suffered mental health issues, with 16% having developed mental health issues after becoming homeless.[6] This data indicates that 1,600 young Melbourne individuals are at high risk of acquiring mental illness if they remain homeless. sIt can be reasonably assumed that state-wide and across Australia the number will be a multiple of 1,600. The cost burden of this to the Australian community, including the loss of productivity must be prevented by the provision of stable, affordable housing. Adult unemployment rate rises to 90% among individuals who were homeless before 15 years of age,[7] further demonstrating the long-term loss to productivity that results from homelessness.

Stable, safe affordable housing has widely been shown to be a first step in the recovery of homeless individuals with mental illness.[8,9,10.11] Not only is there a humane benefit but, by enabling recovery,

[2] https://www.theage.com.au/national/victoria/man-charged-over-murder-of-homeless-david-20120302-1u742.html
[3] Olasji, M., Maude, P., McCauley, K., (2017) Not Sick Enough: Experience of carers of people with mental health illness negotiating care for their relatives with mental health services. *J. Psychiatr Mental Health Nurs.,* (24)403-411
[4] https://www.heraldsun.com.au/news/law-order/stabbing-killer-david-bryan-faces-appeal-for-more-jail-time-over-the-death-of-david-tserniak-in-st-kilda/news-story/a47a5c953a165aab5ef622e37e6350aa
[5] https://www.mhvic.org.au/images/PDF/Policy/FINAL__Saving_Lives_Money_Brochure_HR.pdf
[6] https://www.sbs.com.au/topics/life/health/article/2017/06/27/surprising-link-between-mental-illness-and-homelessness
[7] Saving Lives, Saving Money (2018) Mental Health Victoria.
https://www.mhvic.org.au/images/PDF/Policy/FINAL__Saving_Lives_Money_Brochure_HR.pdf
[8] Pagett D., Gulcur L., Tsemberis S., (2006) 'Housing First services for people who are homeless with co-ocurring serious mental illness and substance abuse' *Research on Social Work 16(1):74-83*
[9] https://housingfirsteurope.eu/
[10] https://www.ahuri.edu.au/policy/ahuri-briefs/what-is-the-housing-first-model
[11] https://streetsmartaustralia.org/5-things-need-know-housing-first-homelessness/

'housing first' facilitates productive economic contribution to community by those affected and in addition, it saves government costs by reducing the need for hospital and other support services.[12]

In summary, society gains many times over from every cent spent on providing supported housing for individuals who are homeless,

2. Prevention and early intervention

Alcohol and drug (AOD) problems are epidemic in Australia. Methods for prevention are beyond the scope of this submission, but early prevention, beginning at schools seems vital, as do improvements in law enforcement to prevent access to illegal drugs and the use of AOD by our young.

The biomedical model of mental 'illness,' which relies largely, and frequently entirely, on expensive pharmacological management of crises is not universally accepted.[13,14,15,,16,17,18,19] Many psychological crises are a call for help, a response to trauma. Addressing the biopsychosocial needs of individuals in crisis has been shown to improve outcomes at less cost than long-term pharmacy, *e.g.*

Open Dialogue (OD)

Established in Western Lapland, in OD psychosis is seen in a family and network-centred context and generally managed in the consumer's home with the help of a multidisciplinary team. At five-year follow up after a major psychotic episode, 82% of individuals were symptom free, 86% had returned to studies or full-time work and only 14% were on disability support, with only 29% having used psychotropic medication at some stage.[20] 'The number of long stay schizophrenic hospital patients fell to zero'.[21] These results contrast sharply with results from a variety of locations where conventional medical treatment results show that over 50% to 80% of similar individuals 'treated' according to the medical model end up on long-term disability support,[22,23] with our local experience being that they join the 'revolving door' of repeated hospital admissions and a life unable to contribute to society, surrounded by family members whose ability to contribute to society is seriously hampered due to their caring role and frequently so compromised by their need to care that they also end up needing government support.

The long-term benefits of eliminating the likely need for lifetime medication and lifetime disability support and the added benefits of economic contribution of individuals and their loved ones to the community have led to OD being adopted in a wide variety of locations globally,[24,25,26] with the Australian New Zealand Journal of Family Therapy devoting an entire special edition to OD.[27]

The concept that individuals in distress need someone to talk to is not new.[28,29] Regrettably, with the chemical revolution of the late 20th century, sidelining talking therapy has resulted in the explosion of

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[12] https://theconversation.com/study-shows-high-public-cost-of-homelessness-3059

[13] Special Edition: (2015), The Biomedical Model of Psychological Problems: *Association for Behavioral and Cognitive Therapies,* (38) 7:169-243.

[14] Romme, M., Escher, S., (Eds), (2012), Psychosis as a Personal Crisis, an experience-based approach. Routledge

[15] Watkins, J., (2006), Healing Schizophrenia, using medication wisely, Michelle Anderson Publishing.

[16] Gosden, R., (2001) Punishing the Patient, Scribe Publications Melbourne

[17] Stasny, P., Lehmann P., (Eds) (2007), Alternatives Beyond Psychiatry, Peter Lehmann Publishing

[18] Read J., Mosher L.R., Bentall R.P., (2008) Models of Madness, Routledge

[19] Williams P., (2012) Rethinking Madness, Sky's Edge San Fransisco.

[20] Seikkula J., Aaltonen J., Alakare B., et al (2006) Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. *Psychotherapy Research.* 16(2):214-218

[21] Aaltonen J., Seikkula J., Lehtinen K., (2011) The Comprehensive Open-Dialogue-An approach in Western Lapland: 1. The incidence of non-affective psychosis and prodromal states *Psychosis* (3)3: 179-191

[22] Clemmensen, L., Lammers D., (2012) A systematic review of the long-term outcome of early onset schizophrenia *BMC Psychaitry 12:150*

[23] https://www.mentalhelp.net/articles/prognosis-and-recovery-factors-of-schizophrenia/

[24] https://www.theguardian.com/society/2015/oct/20/parachute-therapy-psychosis-new-york-uk

[25] http://power2u.org/alternatives-to-hospitalization/#PracticeGuidelines

[26] https://www.health.org.uk/improvement-projects/peer-supported-open-dialogue-pod-in-nhs-mental-health-services

[27] https://onlinelibrary.wiley.com/toc/14678438/36/1

[28] http://www.moshersoteria.com/

[29] https://en.wikipedia.org/wiki/The_Myth_of_Mental_Illness

pharmaceutical costs and the dooming of many unfortunate individuals – consumers and carers alike - to a life of dependency on government support. We have suffered the ravages of 'two steps forward', now it is time to also take 'one step back' and provide optimum care for individuals facing mental health challenges. Talking therapy, Open Dialogue, psychology must have an equal place in recognition and government support for the management of individuals in distress as Medicare and PBS. The benefits of this are not only humane, but financial as well….. talking therapies have been shown to increase not only productivity, but their provision is far less costly than Australia's upward spiral of PBS, Medicare and hospital costs.

3. Issues related to users of mental health services and supports

We do not have an accessible community mental health service.

Individuals needing mental health assistance, but 'not bad enough' to need acute hospital care have nowhere to turn. Lack of timely assistance frequently results in rapid deterioration to severe psychosis, long-term hospitalization, drain on government spending and support – or worse still – loss of life via suicide or tragedies such as David Tserniak's.
The increase in Headspace funding promised via the 2019 Budget promises some hope for youth, but it is not enough. Adults also need community based organizations, preferably Healing Centres to which they can turn to 24/7.

With the introduction of the NDIS, the vast majority of local services which assisted with daily needs have disappeared. This is particularly true in Victoria, where under Mary Woolridge, money for these services was diverted into the NDIS. However delays in accessing the NDIS and that over 90% of individuals with mental health disability will not qualify for the NDIS[36] have left many without the services they relied on. The resultant loss of dignity of consumers and the resultant burden on carers, is immoral, heartless and cruel. Furthermore it results in carers being unable to pursue their own lives and to contribute to the Australian economy.

Fragmentation, Compartmentalization, 'Dual Diagnosis'

It has long been known that substance abuse and mental health issues frequently occur together and for successful management, integrated treatment is required.[30] Despite the acceptance of this co-morbidity and the common reference to it as 'Dual Diagnosis' in Australia, there are few services dealing with the totality of the situation and generally each diagnosis is referred to separate services, each with different waiting times, focusing on separate issues and possibly not 'talking with the same voice'. These related conditions need one service and referring them to separate agencies is total folly not only causing waste of resources, but also penalizing those suffering the challenges of each issue. Individuals with AOD issues are commonly turned away from mental health services because of an AOD problem which shows basic lack of understanding of mental health and denies individuals their rightful treatment, thus leading them to needing government support, making it harder for them to gain recovery and to make economic contribution to our community. AOD and mental health services must become integrated.

Similar compartmentalization exists for other comorbidities. My friend, whose 24 year old daughter suffers from severe mental health and intellectual disability is unable to find accommodation for Eli because mental health facilities do not take on the intellectually disabled and vice versa. Facilities do not provide assistance with dispensing medication so one wonders where young intellectually and mentally disabled adults can reside permanently, safely in dignity without causing burnout of parents and reducing their parents' economic contribution to society.

Physical Health

It has been shown that individuals suffering mental health challenges die 10 to 25 years earlier than the general community.[31] This loss results from a combination of the high levels of multi-morbid systemic conditions including cardiovascular, respiratory, diabetes, infections and hypertension and suicide.[31] At

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[30] Lambert M., Conus P., et al (2005) The impact of substance use disorders on clinical outcome in 643 patients with first-episode psychosis. *Acta Psychiatr Scand* 112(2):141-8
[31] https://www.who.int/mental_health/management/info_sheet.pdf

any time, 80% of individuals with mental health issues are suffering a serious medical condition[32.] with 60% of individuals with mental issues suffering from a chronic disease, 29.3% (n=1,172,000) suffering from one chronic condition and 30.5% (n=1,220,000) suffering from two or more.[33] As the mental health population dies 10-25 years younger than the general Australian population, these astounding rates of suffering for a young cohort indicate a significantly preventable Medicare and PBS burden on the community accompanied by further loss of economic potential of both consumers and carers.

Our mental health services need to be accountable for their lack of attention to the general health of their patients. If a medico knew that a drug for treating (for example) arthritis was closely associated with diabetes and the medico failed to investigate diabetes and to treat it, the medico would be professionally negligent. Yet in mental health, systemic side effects are routinely accepted without management until it is too late. This situation is all the more disgraceful because much of this suffering could be prevented by routinely including dietary and physical health personnel in mental health teams. The low cost of dietitian and exercise physiologist represents moral, ethical and financial investment that would pay off substantially in cost saving from Medicare and PBS and loss of economic participation by consumers and carers.

In our litigious age, it is worth considering what the legal position of services is in regard to informed consent in the context of excessive reliance on medication with serious, often life threatening side effects for conditions which have been shown to respond well to talking therapy. A class action in this context might end up being very costly to our mental health system.

In addition to social factors associated with mental health challenges, such as homelessness, poverty, poor nutrition, tobacco use, AOD and lack of social inclusion, many of the medications used in mental 'health' have side effects which are directly associated with chronic disease, including diabetes, obesity, cardiac and oral health. This is further reason for government to facilitate the use of evidence based talking therapies such as Open Dialogue which result not only in vastly better recovery rates, but also reduced need for medication during treatment.

4. Issues related to carers, family and friends,

Carers, as their loved ones, are victims of a very poor dysfunctional mental health care system. It is because of this system that many are forced to give up their professional lives to becoming carers. In Australia in 2015, of 2.8 million carers, 240,000 care for individuals facing mental health challenges. Of these, 54,000 are primary carers devoting significant portions of their lives to caring and 49% have done so for over 10 years.[34] Conservatively, $1.2 billion is spent on supporting mental health carers, but it would cost $13.2 billion to replace them with formal support services.[34] The economic loss to the community is immense because the $13.2 billion has been calculated at the rate paid for support workers, yet many carers lose the opportunity for economic contribution to the Australian economy via highly skilled professional lives when they are forced into their caring role by the lack of proper help available for their loved one.

The above statistics, from a University of Queensland survey, clearly indicate that carers need far more support, but the best place to start is to improve the mental health system so our loved ones receive care commensurate with care in other areas of medicine. The loss of dignity, human rights and humiliation forced onto individuals suffering with mental health issues because safe, supported accommodation is not available and they are forced to continue living with their parents puts Australia to shame. It also escalates the issues of aged care because when parents head into their 70's, both their offspring and the carers are faced with the dilemma of how to manage their lives and they both fall into needing government assistance - which often occurs much earlier than would otherwise be needed due to primary carers suffering exhaustion and burn-out.

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[32] https://www.equallywell.org.au/,

[33] https://www.vu.edu.au/sites/default/files/australias-mental-and-physical-health-tracker-background-paper.pdf,
   https://www2.health.vic.gov.au/about/key-staff/chief-psychiatrist/chief-psychiatrist-guidelines/equally-well-in-victoria

[34] Diminic S., Hielscher E., et al (2016) The economic value of informal mental health caring in Australia:summary report. Brisbane: The University of Queensland

5. National Disability Insurance Scheme (NDIS).

The challenges of introducing such a ground-breaking and in principle excellent scheme are immense and perhaps inevitable that the initial stages of the NDIS would become 'an aeroplane designed in flight'.

However the many consistent comments from ISFAF members indicate serious shortcomings which should have been foreseen and which must be addressed urgently:

The application process

The application process is designed for articulate individuals with sound cognition, organization and communication skills. By definition, individuals with mental health disabilities lack these skills and are therefore significantly disadvantaged in their application. That NDIS staff frequently have no understanding of mental health, compounds this disadvantage.

Several carers have suffered medical complications such as high blood pressure as direct result of dealing with the complexities of the application process on behalf of their loved ones. Some, successful neurotypical professionals have left planning meetings in tears, shaken by the hostility they have faced from NDIS representatives ignorant of mental health issues.

Untrained / very poorly trained staff

At information seminar, the presenter, unable to answer my simple questions, admitted that she had been hired days before! Her knowledge was scant, but on paper it seemed attendees were being serviced properly. Not only was precious time wasted for all, but the lady was using being paid NDIS money to waste her and our time. What a waste of NDIS money intended to assist consumers to participate in community and to make economic contribution to community!

ISFAF members consistently complain that planners and other NDIS representatives have no understanding of mental health.

The ongoing process

I cannot comment on other states, but in Victoria, many services to assist with daily living and social inclusion have closed. Closure has resulted in the loss of trained mental health workers who have been forced to find employment elsewhere. The situation is chaotic as some individuals who have managed to obtain approved plans are unable to fulfil them due to:
- delays in accessing their rightful funding,
- inability to find workers / services able to provide the needed help,
- if plans can be set into motion and an organization found to implement a plan for someone with mental health disability, service providers send a series of workers, some without mental health skills and therefore lack of continuity of care results in very poor care.

To earn that the money for professional services is available but 'unspent billions' have effectively been stolen from the disabled[35] is horrifying for consumers and for carers who are yet again left in the position of needing to forego their own lives and their right to participate in, and contribute to, the Australian economy.

Outside the NDIS

It has been reported that about 90% of individuals with mental health disability will not qualify for the NDIS.[36] This is partly because of the episodic nature of mental disability. These unfortunate individuals

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[35] https://www.theaustralian.com.au/nation/politics/unspent-billions-shifted-from-the-books-of-ndis-agency/news-story/62fbd169e1f97b73d384439947d6e55,
https://www.theaustralian.com.au/nation/politics/ndis-has-5bn-but-costs-to-soar/news-story/6026e5c16c82f8b42438

[36] Hancock, N., Bresnan, A., et al (2018). NDIS and Psychosocial disability – the Victorian Story: Insights and Policy Recommendations from Expert Stakeholders. *Report prepared for Psychiatric Disability Services of Victoria and SalvoConnect.*

have been left to their own devices because of the closure of the services upon which they relied. It can be expected that the mental and physical condition of consumers and their carers deteriorate as a consequence, that their economic contribution to Australian society is reduced and they become a greater burden on government assistance.

In conclusion

The increase in access to Headspace is a very welcome step in the 2019 Budget, as is other additional funding earmarked for mental health and associated needs. It needs to be seen whether the additional funding is sufficient to address the need, but spending it wisely is a must.

Overarching difficulties currently experienced are the complexities of funding, some of which is via the Federal Government and some via the States, allowing each to point to the other to address vital needs of the mental health community.

Mental health occurs on a spectrum and needs to addressed as one issue from 'minor' short 'unwellness', to severe chronic conditions. Fragmentation in funding and fragmentation in services both lead to waste of government resources and to compromised outcome. Establishing an integrated stepped care service able to deal with multi-morbidities including smoking and AOD would provide a system that is preventative of further deterioration wherever possible[37] and therefore would save money in cost of services and it would boost economic contribution to Australian society by both consumers and carers.

Such services need to be community based and 24/7 accessible. Currently there are a few community based services, but access is difficult, few individuals needing their services are aware of them and/or have easy access to them. All in Australia need somewhere they know they can turn to in times of need and receive humane support. Being doped, placed in 'high dependency units' which resemble solitary confinement in a correctional facility or being refused help because one is 'not unwell enough' are not acceptable responses to mental distress in an advanced society.

The 'two steps forward' to almost universal acceptance of a medical, pharmaceutical model of 'care' must cease. While medication has a definite place, it is not an easy panacea. Fortunately, a holistic approach is not only humane but also cheaper to fund and brings greater economic participation by consumers and carers – an economic 'win-win' to consumers, carers and Australian society as a whole.

Another reason to reduce the role of medication where possible is to reduce the serious toll of physical harm that is directly attributable to the side effects of medication, particularly psychotropic medication. The list of dozen(s) of legal drugs taken daily by some consumers is terrifying, Drugs are not a panacea and need to be monitored carefully. In an Australian study undertaken in eight hospitals pharmacist initiated monitoring of medication saved $23 for every $1 spent.[38] Although this was not mental health specific study, from the dozen(s) of daily medications taken by many mentally ill patients, there is likelihood that similar savings can be had in mental health.

If you spend our money wisely, it will be returned many times over to the Australian economy.

Judith Burstyner, on behalf of Inner South Family and Friends   5 April 2019.

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https://probonoaustralia.com.au/news/2018/03/ndis-causing-growing-catastrophe-victorians-severe-mental-illness/?utm_source=Pro+Bono+Australia+-+email+updates&utm_campaign=72cf2f8458-EMAIL_CAMPAIGN_2017_08_18&utm_medium=email&utm_term=0_5ee68172fb-72cf2f8458-147645121&mc_cid=72cf2f8458&mc_eid=638c213cfb
[37] https://mhfa.com.au/sites/default/files/vol2-review-mh-programmes-services.pdf

[38] Dooley MJ., Allen KM., et al (2003) A prospective multicentre study of pharmacist initiated changes to drug therapy and [patient management in acute care government funded hospitals. *Br J Clin Pharmacol 57(4)513-521*