

3rd April 2019

Australian Government Productivity Commission
4 National Circuit
Barton ACT 2600
Inquiry into Mental Health

Productivity Commission Inquiry into the Economic impacts of mental ill-health

Altruism comes with a price.

I welcome the Commonwealth Government's commitment to promoting the health and wellbeing of Australians at all stages of life, and thereby appreciate the opportunity to make an individual submission to the Productivity Commissions Inquiry into the Economic impacts of mental ill-health.

My submission is based on the challenges of **voluntary and paid participation of the lived experience workforce.**

I respectfully request that the inquiry takes into consideration **the importance of demonstrating the value of lived experience knowledge, skills, time, and commitment being offered to the health and wellbeing of Australians, as this workforce grows.**

Attention to more equitable remuneration is long overdue, all the more as this perspective is becoming an important complimentary health service, an important professional and vocational opportunity.

Volunteering versus Paid Participation

Wanting to give back to community using the lived experience of managing life with mental illness and surviving suicide is deeply rewarding. Endeavouring to alleviate one person's pain who maybe travelling on a similar path, gives the lived experience meaning, helps recovery through connectedness. Finding "common ground" with "someone who "gets it." (NESTA, 2013)

Giving of oneself, sharing vulnerability and offering support, gives others permission to share their lived experience, to feel hope and that recovery and rebuilding is possible.

Often this "giving" comes at a high cost.

Over 19 years, I have used my lived experience of recovery, managing bipolar disorder and surviving several suicide attempts through various roles and activities in the hope of reforming Australia's mental health system and how we as a society manage suicidal behaviour. In doing "advocacy" work, and sharing my lived experience loudly and publicly, I very quickly became estranged from a parent

and some family members due to the power of stigma and shame. It has been nearly two decades that I love them from a distance. No, I wasn't going to give up what became a personal crusade and my calling.

Mental health and suicide prevention faces a major workforce shortage. We can never meet demand, so services need to be innovative.

Consumer participation has been enshrined in our national mental health policies since 1992. As part of a now rapidly growing global social movement, the lived experience as a workforce of peers, peer support, consumer and carer advocates offers diverse vocational and professional career employment opportunities (Australian Health Ministers, 1992., Gordon, & Bradstreet, 2015., Meagher, Stratford, Jackson & Fong, 2018, Australian Government, National Mental Health Commission, 2018) .

There is also tension between service providers and the lived experience. The former are feeling threatened, perhaps their roles will no longer be needed? There isn't clear understanding of what peer support, peer support workers do, their roles are not always clarified, how they can enhance and compliment the work of other health professionals in case managing an unwell person? How are peer workers to be accepted and integrated into services? Programs? (Byrne, L. Stratford, & Davidson, 2018, St George, O' Hagan, Bradstreet & Burge, 2017).

There is strong evidence that peer support/lived experience helps people with wellness and recovery from a range of health issues, including helping individuals to cope with stress or emotional and psychological challenges, engaging with communities that are difficult to reach, and reduce admissions to hospital. Generally being a cost-effective and cost-saving complimentary option that presents an opportunity for health care planning and management (Peers for Progress, 2015).

A major challenge exists in how best to acknowledge the value these perspectives, experiences, knowledge and skills contribute to the mental wellness of our community, and in suicide prevention. How do we acknowledge innovation, the giving ideas, sharing, designing, developing, implementing, delivering, monitoring, evaluating of programs and services for the human condition, time to read and comprehend and review complex materials and concepts?

There is has been and still is to a large degree, an expectation that these contributions and services are pro bono. Volunteering suits many people, but doesn't work for everyone. Others try a combination of employment for salary and volunteering for causes of personal meaning and pleasure. Generally though, volunteering can only go for so long, unless the individual has economic circumstances allowing them to.

In some organisations across the mental health and suicide prevention sectors, remuneration or recompense is a given, but this is not consistent across the entire industry (Bennetts, Pinches, Paluch, & Fossey, 2013, Burge, & Child, 2011, St George, O' Hagan, Bradstreet & Burge, 2017).

So when is asking and receiving something or a service for free unfair or even unethical (Payne, C. 2018)?

Those who work in this way daily, spanning years and decades and who may not have wealthy circumstances some how continue volunteering. Pain, anger, passion, love can be powerful fuel to try to make something better, even under adversity and perhaps not always in one's best personal interests. Money is rarely the motivator, but we all have financial obligations. Caring too much finds day to day (and future) economic realities stressful for the volunteer and their families.

Participation comes in many forms; voluntarily, as mentioned, but also via tokens of appreciation, such as vouchers, honorariums, or sitting fees - that don't always take into account extra work and time, or skills required to participate or complexity of work, consulting and/or salaries via employment. Some dedicated advocates who are employed use all their annual leave to do extra advocacy and/or educational activities

An example of inequity;

Every few years only 60 consumers and carers are selected onto the National Mental Health Consumer and Carer Register auspiced by Mental Health Australia and linked to the National Mental Health Consumer and Carer Forum. Government bodies, NGO's, and others who know of this register use this to appoint lived experience voices, consumer and carer advocates, or representatives to their table or project. These are mostly national paid roles with payments established by The Australian Government rates set by the Commonwealth Remuneration Tribunal (as at 2013) for reimbursement of consumer and carer participation. A policy as used by National Mental Health Commission, and other government agencies.

This register has a mix of people, some with years of experience mentoring upcoming future leading registrants. A positive initiative, this was established to provide wider opportunities for more consumers and carers to participate in advocacy and leadership roles at a national level. In the early days, when the movement was smaller, there was a sense that advocates were not being fairly selected, but rather tapped on the shoulder. Ironically, this model perpetuates similar practices, excluding many. Why is this not open to all consumers and carers?

There are more discriminatory practices....

Our higher profile mental health and suicide prevention colleagues/charities have government funding to establish extensive "lived experience databases." Whilst doing admirable work, the practice of recruiting people to speak about their lived experience, their pain and vulnerability. It is expected predominantly pro-bono. Remuneration is far from adequate, if at all and are required to request donations from the audiences. This of course gives the organisation marketing, branding opportunities at no cost!

The lived experience voices enjoy their work and opportunity to bring change but they may be uncomfortable to say anything about payment as they love what they do and enjoy being able to represent a well-recognised mental health and/or suicide prevention organisation.

Yet, paradoxically, these very voices will complain in whispers outside the offices, but don't say anything to management as they don't wish to be viewed negatively (and also not lose out on possibly paid work that we all are hanging out for).

It is very hard to say no.

But this is taking advantage of generosity of spirit and exploiting people who wish to make a genuine difference. Those who do find the courage to say something, to decline doing something for nothing or raise fair questions diplomatically and assertively are considered to be troublesome and divisive, and are excluded from participating, ignored. Often they are bullied.

What message does this send to community and the lived experience contributors and workers coming up behind us that will be our leaders tomorrow? **This sets a terrible backward precedent.** Society pays for what it values.

Not remunerating lived experience for their contributions is also demoralising. We all talk of the importance of volunteering to mental healthiness, but it can also hinder and hurt our self-worth.

Giving “us” our “messages and skills” away not only devalues the individual but it devalues and demeans us all, what we do and are striving to do. Giving things away constantly though important and admirable, comes at a cost.

Add in the stress at seeing the same wealthy charities appearing to be spending excessively on expensive, “glossy” resources, clever mass marketing, savvy social media advertising all through government funding to hold “fundraising parties” for community members to keep donating, and something doesn’t seem fair.

With unknown numbers of people within this sector providing pro bono work, or at very little recompense, the value of the contribution to society now and in future generations is difficult to quantify financially.

The lived experience workforce, as with the entire health sector, all need support and resourcing to continue our loving painful life and death work. We are putting ourselves and our mental health at risk of burning out, experiencing or potentially experiencing vicarious trauma every day we give ourselves, to try to make something better.

We are also struggling to contribute to our financial future adequately, e.g superannuation and therefore paradoxically some of us will probably need a pension.

This is also an industrial relations issue that will eventually flare up.

The very real alternative is for many gifted skilled experienced people to walk away with rich sector and lived experience knowledge that can and does help countless people to stay safe and work towards recovery.

If many of us do this, on top of those retiring as we are an aging population, the loses will be incalculable.

Recommendation;

Lived experience to be offered choices of remuneration, either voluntary or not.

Government committee membership, advisory board, as with many, payment to equal for all members, irrespective of title, slightly more for the chairperson e.g. Better Access – GPMHSC (General Practice Mental Health Standards Collaboration) pays/paid all committee members the same amount, whether psychiatrist, psychologist, GP, consumer and carer and take into account extra reading time and complexity).

Remuneration that is equitable with other stakeholders at the decision making table

For organisations who wish consumers and carers to be speakers, presenting their lived experience to be paid appropriately, including preparation and delivery time, plus any transport expenses.

This raises the issue of evaluating all our charities financial records very carefully, including advertising and marketing expenses, salaries of employees and board member expenses. Awareness is important, but it is time to move on to education and service provision. The monies being used on these activities, plus the donations and government funding received might be an opportunity to call out our wealthier colleagues to remunerate the lived experience peer support workers that they call upon regularly.

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