Committee Secretary
Senate Select Committee on Mental Health
Department of the Senate
Parliament House
Canberra ACT 2600
Australia

Dear Sir,

Thank you for the opportunity to make a submission to the committee and I sincerely hope your efforts do not fall on barren ground, like so many others that have tried to address the significant problems in our failing mental health system. This submission represents my personal views.

I have over 20 years experience working in the mental health system in NSW and Queensland. I began my career as a nurse and graduated in psychology in the early 80’s and have worked in both professions since in a variety of settings and positions including: psychologist mental health crisis team; community clinical psychologist; nurse on General Hospital inpatient unit and within a large Schedule V hospital; Lecturer and Senior Lecturer in Mental Health and for the last 10 years I have been researching recovery from serious mental illness from a consumer perspective in Australia, USA and Italy with professional colleagues. In addition I have been invited to speak on recovery in a number of countries and been Vice President of the Queensland Association for Mental Health.

This submission will address Terms of Reference a, e, i, n, o. and I am happy to offer any assistance to further the committee’s objectives.

Yours sincerely

Barbara Tooth RN., BA (Hons), PhD

a) the National Mental Health Strategy (NMHS) has achieved its aims and objectives and the barriers to progress

Unfortunately the NMHS has failed to achieve its aims and objectives. Whilst Australian policy documents are some of the best in the world, their implementation appears to be some of the worst. There are a number of barriers to successfully implementing the NMHS:

- Failure to adequately fund the wide range of services and supports (including housing and vocational) needed to support people. The action to provide a range of services to meet people's self-defined needs has not been realised.
- The ultimate aim must be to assist persons with mental disorders to occupy the citizen space with dignity. The current statistics show that 83%of persons with schizophrenia in Australia are unemployed.
- The failure to fund is indicative of the much larger problem of a failure of Federal and State Governments to have a genuine commitment to improving the lives of people who have the lived experience of mental distress and their families. The fragmentation of service /support delivery systems is highly visible in Australia. This is due to the basic needs of a person met by a number of different organisations funded by different levels of Governments and different departments within the Govt. People with mental disorders should have access to a service/support delivery system that is seamless, local and capable of proactive and timely ability meet people's needs.
- Commitment is evidenced by genuine human concern, advocacy and action to protect and promote the rights and dignity of people to live meaningful lives within the community of their choice. All policies and guidelines should boldly reflect the philosophy of hope and recovery.
- The scarce resources that are available are now being ploughed back into building new inpatient units and rehabilitation units. The research conducted in Qld by my colleagues and myself found only 12 % of participants reported hospitalisation to be beneficial and this was primarily because it provided them with a place of safety rather than treatment. We have had similar findings in USA. There appears to be reluctance in the community, carers, professional policy makers and bureaucrats in accepting that people experiencing mental health crisis need a lot of choices of where they are cared for as alternatives to hospital admission. The evidence for beneficial effects of hospital admission for persons with psychiatric disorders is minimal. There is enough evidence suggesting the toxicity of hospital admissions as they currently exist. Hospital admissions de-contextualise people (enforce stigmatising attitudes), disengage people from their valued social supports, promote social disintegration and entrap people in the career of psychiatric patienthood. This is further consolidated by our welfare system and paucity of real supported employment opportunities that is uniformly unavailable throughout Australia.
- The governments' actions suggest a mental health agenda driven by people other those it is meant to serve. We have a "top down" rather than "bottom up" organisational structure and attempts to redress this through genuine collaboration and partnership have failed. True and genuine commitment to

listening to and responding to the consumer voice must become enshrined in the reform agenda.

e)[1] *unmet needs in supported accommodation, employment, family and social support services is a barrier to better health outcomes*

- As previously mentioned one of the barriers is that we do not have an integrated and seamless, easily accessible integrated system of care that addresses the *range* of services to meet the needs of people who have the lived experience of serious mental distress to overcome the barriers to better health outcomes.
- Mental health services only a small but important part of the greater range of needs for people who have the lived experience of serious mental distress.
- Yet we continue to focus on the MHS as if it were the main requirement for people to recover. This is simply not true and actually harmful.
- Further, consumers need to decide what it is they need, not professionals because we have not been good at getting it right.
- Warner (1994) documents the results of mental health outcome studies over the past 100 years and shows outcome is no better now than it was then.
- If we are serious about better outcomes there needs to be a whole of government and community commitment to them and a concerted effort made to ensure people are able to live meaningful and productive lives within the community, a fundamental human right.
- Outcomes we look for should reflect what the consumers wish for namely, illness self management, crisis self management without hospital dependence, residential stability, vocational outcomes and living a life (not just free of psychiatric symptoms).

i) opportunities for reducing the effects of iatrogenesis and promoting recovery-focused care through consumer involvement, peer support and education of the mental health workforce and for services to be consumer operated

Iatrogenesis

- In 1967 Paul Polak wrote an article, “The crisis of admission”, detailing the iatrogenic trauma associated with psychiatric admission. In Australia Fiorelli has shown this to still be the case today and our extensive research provides verbatim accounts of this on which I can elaborate.
- People experiencing serious mental distress are vulnerable to trauma because of the way they are treated within and by the mental health system.
- Mental health professionals are not ill intentioned. They are often well meaning and dedicated. However the way we interact with people plus our inability to provide the range of services needed to support people to stay in the “least restrictive alternative” unnecessarily creates trauma.

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[1] From our research I can provide extensive accounts of what people, who have the lived experience of serious mental distress, have told us about their unmet needs.

- Mental health care systems therefore should have a good understanding of the unintended consequences of delivering services in a traditional way and constantly ask what supports and promotes self directed recovery & what hinders it?

The significant challenges to promoting recovery focused care.

- It has to be a whole of government approach
- There needs to be widespread collaboration with the community so as a society we work together to improve mental health outcomes
- Care needs to be based on values beliefs and attitudes that support promote and facilitate people's self directed recovery in contrast to a focus on skills
- The workforce needs retraining in the provision of recovery practices and this has to be taken seriously to ensure this becomes a reality. In sum, we need to use our humanity in such a way that it is healing.
- The MHS is only a part of the much bigger picture of what is needed to facilitate recovery. This will necessitate devolution of power within the MHS.
- Lastly but most importantly it has to be the consumers who drive their recovery because it is only something they can do. It is our responsibility to assist in facilitating this process.

Consumer involvement

- There appears to be a significant number of people (50%) who experience serious mental illness who do not come into contact.
- Some of this is the reflection of a dysfunctional system
- However a significant number of people *choose* not to come into contact with the MHS because of their belief it would not be in their best interests to do so. *We have a lot to learn from these people and this is a research imperative, my colleague Dr Kalyanasundaram and I would dearly love to undertake*.
- There are few examples of *genuine* consumer involvement because of the attitudes, values and beliefs of those with the power to ensure this occurs.

Education of the workforce – A personal reflection

My experience of having Multiple Sclerosis illustrates a problem systemic to health care in general. It is seductive to believe the MHS is the only area where education of the workforce is a problem, however this is not the case. My experience resonates with many people's experience of contact with the MHS.

- Once diagnosed, I was offered "the" range of medical treatments. That is, I was asked which of the available injections would you like. Treatment revolves around symptom management and what "experts" believe important.
- Yet for me whilst symptom management is important the major impact this disorder has had on my life is far more so.
- However I have had virtually no assistance with this. I do remember going to a clinical psychologist who used the analogy "well you have been at the top of one ladder, now you are going to have to go to the bottom of another and start

again". This wasn't comforting. Nor was it comforting when I raised these issues with my neurologist back then who told me "Universities were nothing more than sheltered workshops so I should feel lucky that with my cognitive deficits I would fit in and no-one would notice". At the time I was a senior lecturer responsible for the design, coordination, development and teaching of a post-graduate diploma/masters degree in mental health.

- The times when I really feel truly heard and my experiences validated is when I speak to other people who have MS. The usual invalidation of my experience that occurs when I talk to most other people just doesn't occur. I know other people are well intentioned but they just "don't get it". I believe this is reflective of the nature of experience and people's ability to truly "step into the shoes of the other".
- Over a year ago I went to the Gawler Foundation for a week residential on Taking Control of MS, based on Professor George Jelinik's book. It has been George's work that has the major impact on my life because he has focused on how I can be an active participant in relation to MS rather than a passive recipient. I have made a number of changes as a result and it is these that have significantly improved my health. Plus I keep in contact with the wonderful group of people who also attended the course and we have a forum where we can be open and free in discussing our lives.
- George Jelinik is a Professor of Emergency Medicine and he has MS. He did not take the advice given to him and went searching for his own answers and has found many and the search continues. Yet the mainstream MS societies and MS practitioners do not take him seriously, will argue about the validity of his work and claim "he was misdiagnosed" to explain why he is doing so well.
- The message is "don't buck the system or we will ostracise you".

The consumers in our research report very similar experiences with the mental health system, however for people who have the lived experience of serious mental distress their experiences are much worse. Not only do they have to deal with a disorder that more severely attacks their sense of self, they have to deal with a service that does not validate them or go anywhere towards meeting their needs.

Education of the workforce – A professional reflection

PhD thesis – a few relevant points I can elaborate on significantly

- My PhD thesis "Mental Health Professionals Construction of their Clients" (1992) set out to understand how mental health professionals make sense of what they do they when they work with people.
- It was an in depth qualitative and quantitative study and one of my findings was that only 3% of participants reported their education/ training actually being of benefit to the work they were required to do. For them they were relying on the values and beliefs they had prior to their education. That is, they were relying on their humanness.
- Another interesting finding was the higher the level of study undertaken the more likely people were to report there was so much more they didn't know.
- My thesis provides considerable support for generalist mental health workers.

A few reflections of an academic that again can be extensively elaborated

- Educational programs that focus on skills at the expense of attitudes, values, beliefs and ways of working that facilitate and support people's self directed recovery (such as narrative approaches) are doomed to maintaining the grossly inadequate status quo.
- Educational and training programs need to focus on what the person needs from us in order to facilitate their recovery rather than what is it that we need to become "expert" professionals.

Consumer operated services - to name just a few examples and illustrative of invaluable role of employing consumers within a broad range of services.

- Serious consideration has to be given to a vast range of peer support services that can provide alternate models of care and these have a good working relationship with the current MHS so people have a real choice. Meta services in Phoenix Arizona (www.metaservices.com) provide a very good model of service provision. They also provide a significant amount of eduction for their workforce. I refer you to this website.
- The work cooperatives in Trieste Italy provide an excellent example of consumer operated commercial businesses that provide *real* employment for both consumers and the general public.
- The question that urgently needs to be asked is what funding and other supports are needed to truly support the consumer /carer movement to provide a range of meaningful functions alongside the professionals?

I refer you to the following publications.

Tooth, Kalyanasundaram & Glover. (1997) *Recovery from Schizophrenia: A Consumer Perspective*. Report to Health and Human Services Research and Development Grants Program, Canberra Australia.

Tooth et al (2003) Factors consumers identify as important to recovery from schizophrenia. *Australasian Psychiatry*, 11(1), pp 70-77.

Tooth & Stanton (2005). The context of practice. In Elder, Evans & Nizette (Eds) *Psychiatric and Mental Health Nursing*. Elsevier Mosby Sydney.

n) the current state of mental health research, the adequacy of funding and the extent to which best practice is disseminated

I talk from personal experience as a researcher, specifically since I left my academic position as a Senior Lecturer in a Qld University due to the effects of Multiple Sclerosis.

- Research funds are grossly inadequate.

- The research money that is available drives the research agenda eg drug company research grants.
- There are miniscule funds for researchers outside academe.
- I have found it impossible to obtain research funds since I left my tenured University position. It is "as if" I had left my research skills and abilities behind, yet my passion and enthusiasm to continue the work I started remains very much in tact but now a voluntary endeavour.
- The research undertaken by Dr Kalyanansundaram and myself in 2003 was unable to obtain any research funding due to the small allocation of funds for qualitative research looking at people's lives. However there are significant funds to research symptom reduction. The disproportionate allocation of research funds must be addressed as well as the role of drug companies in this process.
- A part of the problem is the political nature of the review process for research applications. The "experts" often view the qualitative research we undertake as "soft" research as opposed to the "hard" evidence provided by quantitative methodology. Yet this ignores the fact that in areas where little is known about the object of study (eg what consumers believe helps or hinders their recovery) research has to be exploratory and descriptive and therefore out of necessity qualitative. We take considerable effort to add methodological rigour to our work yet this is ignored due to what I believe is a research bias.
- Who drives the research agenda and how research findings are disseminated and discussed must be addressed. I believe there can be quite elitist and club like views on what constitutes valid areas of research. Further, if the research findings challenge the status quo there appears to be a culture of "shooting the messenger".
- I support the above statement by the numerous experiences I have had when presenting our work at conferences. Invariably consumers congratulate us, thank us and frequently comment, "yes that is what it is like for me, and at last someone is listening". Yet professionals often challenge us and attack the validity of our work. I believe this is because our findings significantly challenge their fundamental positions. However internationally our work is recognised for its significant and important contribution to recovery research. Am I bitter and twisted? I don't think so.
- Evidence based practice provides a significant dilemma to research that is not being addressed.

o) the adequacy of data collection outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards

- Outcome measures need to be consumer driven, if they aren't then their validity and reliability is highly questionable. We need to stop the pretence that experts know best and it is they who know what indicates a good outcome. The person receiving the service can only determine what constitutes a good outcome. Therefore measures need to be developed in collaboration with them.

- Current measures such as the HoNOS focus on deficits, clinical symptoms, activities of daily living etc. However these can bear little relationship to whether the person feels they are living a purposeful and meaningful life with or without illness, the ultimate outcome measure. Such measures are certainly not recovery orientated and contradict recovery-orientated practice.
- Warner's (1994) review of outcome studies over the past 100 years found no difference in outcome now compared to 100 years ago. Given the significant changes that have occurred in mental health and the mental health system since then begs the question "Why and what implications does this have for outcome measures, systems of quality control and monitoring and evaluating mental health services"?
- I have a great deal of concern about linking funding to compliance with the national standards. Whilst the national standards are excellent, assessment of their attainment needs serious discussion. A point made by Dr Phillips at the 2004 TheMHS Conference. Many of us have experienced the accreditation process either within our own services or in others and are well aware of the "polishing" act that goes on immediately before assessment and it has to be questioned how services that we know are severely compromised could possibly meet the standards.
- Talk to consumers and their families and I doubt services would pass and more than likely fail miserably. Therefore attention has to be paid to the assessment process, particularly to the involvement of the key stakeholders in this endeavour. It would be good if services had the courage to fail so the real issues could be addressed rather than just continuing to play the paper game. It appears the paper is the only thing you need to validate and justify the service.

The critical point is that we have a health system that is threatened by the radical change needed to meet people's needs, improve their lives and significantly increase better health outcomes. Change is threatening and requires courage. Sadly, it is my personal belief the MHS from the Prime Minister down are not up to the challenge. Neither are their state counterparts.