SUBMISSION TO SENATE INQUIRY INTO THE PROVISION OF MENTAL HEALTH SERVICES

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SUMMARY

Comments are made on the

- **the inadequacy of the slogan" One in Five Australians have a mental illness" and similar slogans**
- **the need for reliable figures on**
    1. **incidence of mental illnesses**
    2. **level of impairment experienced within the various categories of mental illness**
    3. **"recovery" rates**
    4. **treatment needs**
    5. **accommodation needs**
    6. **employment participation**
    7. **general health problems among people with mental illness**
- **the need to acknowledge problems associated with anecdotal evidence.**

Until reliable data is available, improvements will tend to be of a band aid nature.

Reference is then made to various aspects of the terms of reference where I consider I have insights worth sharing. They include:

- **modes of care for people with a mental illness.**
- **The extent to which unmet need in supported accommodation, employment, family and social support services is a barrier to better mental health outcomes**
- **Employment**
- **Comorbid Conditions**
- **Training of and Support for Family Members.**

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Rather than address the terms of reference directly, I wish to draw attention to some issues which must be examined and some statistics which need to be more accurately assessed before lasting and continuing improvements can be made to mental health services.

I have been close to people with mental illness including members of my family for almost fifty years. In recent years, I have been closely associated with organisations concerned with mental illness, including being a former president of Canberra Schizophrenia Fellowship, former president/manager of Mental Illness Education ACT and I am currently a carer representative with Mental Health ACT.

- I want to emphasise the **inadequacy of the slogan" One in Five Australians have a mental illness".** The term mental illness leads to confusion about the nature of such illnesses and is so all embracing as to be meaningless.

  The term "mental" illness is misleading because so many of the illnesses thus named are proving to be associated with physical or chemical changes in the brain, changes which are sometimes influenced by chemical changes in other parts of the body. Much of the stigma associated with mental illness springs from false perceptions that such illnesses are psychological and/or arise from lack of character, self control or strength of will when this is far from correct. Schizophrenia is just as physiologically based as diabetes.

  The "one in five" covers such a variety of conditions as to make generic statements meaningless and useless. The conditions can range from a mild, short term, non- recurring reactive depression to a treatment -resistant life long schizophrenia which completely takes over a person's life.

  Every person with a mental illness, regardless of the diagnosis, is slightly different and may have quite different needs from others with the same diagnosis. The needs of people with different diagnoses varies very much. For example, some people need to be encouraged to leave acute care. Others need to be strongly encouraged before they accept any care at all.

- In a similar way the use of the generally accepted figures **"one in a hundred people have schizophrenia" presents the same problems.** The figure may include people with very low key symptoms, people with symptoms controlled with medication, people who have periodic episodes or people who are treatment -resistant. It can include people who can work full-time in demanding jobs, people who can work part-time or on short projects and people who cannot concentrate at all. It may or may not include people who are undiagnosed or who refuse to disclose symptoms except in a very unspecific way.

- **Reliable figures do not seem to be available which would give factual information necessary to address the terms of reference in a practical way**. Are there accurate figures, specific to particular areas, about the **level of impairment experienced within the various categories of mental illness.** Until this is done, I cannot see how judgements can be made about adequacy or inadequacy of services available. On the other hand, improvement should not wait for the figures, but they do need to be collected. If they do exist, they do not appear to be used to establish the level and type of serbvice required.

  Again there seem to be big gaps in the figures about effective service, successful treatment and reintegration into the mainstream community. Some figures would gloss over the extent of disability because they count separations from service, not the level of recovery. Separations from the service can be for lack of resources or lack of co-operation of the client.

- Some **figures** are available which indicate a **lack of suitable accommodation** for people with mental illness in the ACT. Each month, figures are issued for supported accommodation. There are very rarely any vacancies. Demand appears to outstrip supply. There appears to be no attempt to collect figures for people who are currently in inappropriate accommodation and who need more support. No figures appear to exist for people who are currently supported by family members in a family home or in nearby independent accommodation, but who need, or will need in the near future, access to supported accommodation. Many adult children with aging parents are in this situation.

  I doubt if accurate figures exist which track the connection between a lack of suitable accommodation and figures for readmission to hospital. Studies from America report better levels of recovery where there is strong family support. Studies are needed to see what sort of accommodation, if any, is linked to positive outcomes. There are projects in the UK which might provide such information. Is any work being done in Australia.

- Be wary of figures that state **success rates for return to work**. In their efforts to increase employment opportunities for people with mental illness, peak bodies, like MHCA tend to emphasise the possibilities for success. Even the most successful programs in other countries, have 50% of people in some categories of mental illness unemployed. MHCA acknowledges this. **The situation of people who cannot work must not be overlooked.** In no circumstance, should assessment of ability to work be based only on diagnosis. Even the best treatment is not always successful in removing symptoms. The severity and nature of each person's symptoms must be judged individually. There is a real danger that underdeveloped return to work programs work will result in an exacerbation of symptoms.

- The **figures for people in prison** who have a mental illness also need to be refined. Discussions about the percentage of people in prison who have a mental illness invariably confuse those who have become depressed because of the conditions in prison and who have a chance of a good recovery, those who have a severe mental illness, but whose associated impaired judgement, rather than psychotic symptoms, caused their criminal action, those who have been psychotic and those who continue and may continue to be psychotic. Very different solutions are needed to deal with the range of people involved.

- Figures need to be established for **general health problems among people** with mental illness. Indications are that comorbidity rates and mortality rates are unacceptably high regardless of figures for suicide. We need to know these figures so that appropriate programs can be devised and implemented. (A cynic from a utilitarian philosophy might ask does the community want to improve life expectancy for people who tend to need ongoing treatment and income support. I come from a different philosophy.)

- The inquiry will receive a great deal of **anectodal evidence** about the inadequacy of services. For various reasons, the inquiry is unlikely to hear from people who are satisfied with the service. For example, stigma is still so great, people who are coping reasonably well will not want to draw attention to themselves.

  Anecdotal evidence can be out of date. Situations can improve or deteriorate quite rapidly. It can come from people who are so shocked, angry or distressed and who wish to find some one or something to blame. Two families can have much the same experience and describe it in quite different ways.

  Uninformed people can be unaware of successful practice in other places and can be seeking services that are no longer considered to be the best option. Comparisons are made between Australian States of the number of beds available per capita. There seems to be no comparison with programs, worldwide, which might have the potential to treat people in a way that minimises the use of hospital beds.

  Hence, one hears calls for more beds instead of calls for much better treatment in the community and more appropriate accommodation in the community. Inpatient services are expensive, but could be minimised if sufficient resources were put into the more efficient and cheaper community care. (Unfortunately, in the past, community care has been treated as a cheap option. Good community is not cheap, but it is cheaper, for obvious reasons, than inpatient care.) If figures for this are available, they are not widely publicised.

- **Dissatisfaction with services provided often stems from a lack of understanding of what services can do**. Even the best of treatments are not yet fail safe. Frustrating as it may seem to bystanders, especially families, individuals who are ill do have a right to refuse treatment. Some do so through lack of insight or misinformation; some for very sound reasons and good understanding of the effects of treatments. Some people who are ill hide their symptoms even from treating doctors. To minimise the results of such behaviour, skills of individual doctors and nurses need to improve. Quality control needs wider implementation.

Not all suicides can be prevented. I would like to think that life can be made meaningful and less painful for some people with treatment resistant schizophrenia, for example, but I am learning by experience that this is not always so. I understand very well why some people want to escape from their suffering by ending their lives. I would like to offer them hope but I will not judge them.

Very few people understand the suffering of some one experiencing psychotic symptoms. They tend to judge them for the inconvenience or hurt they cause to others without realising that the person who suffers most is the person with the illness. The presentation of simplistic, overly optimistic prognoses and solutions increases the suffering of the person who is ill, ultimately causes anger and misplaced blame from relatives and members of the general community.

None of this is meant to imply that services are adequate, just that I doubt if accurate information is available to establish what the needs are. Similarly, I am sure that the inquiry will receive some submissions that are not aware of best evidence based practice in the field of mental illness.

In all of these areas, there are people with better information than I have. From past experience, I am afraid that what they will have to say may be overwhelmed by the emotional and very tragic individual stories many people have to tell. However, individual stories must be put into context. I raise my voice in the hope of adding to comments on wider issues some of which may be overlooked.

Following are my comments on some areas mentioned in the of the terms of reference in which I have had particular experience.

The adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care.

In my experience **too much emphasis is placed on acute care hospital units and insufficient resources are allotted to community care.** Many people with mental illness are unhappy and frustrated in hospital especially if they are involuntary patients. This impedes improvement in their condition. Their health and well being is not improved by mixing with people who may have very different symptoms. Their isolation from the community is emphasised and this in turn exacerbates their condition.

However, the community care provided at the moment appears not to be adequate to replace hospital care. People should have access to care in their own homes for extensive periods of each day and be assisted to attend constructive activities, preferably not exclusively attended by people with mental illness. My son has the benefit of very good community care, but he would need more than is currently available if I was not determined to be support him almost 24 hours a day when necessary.

Respite care, away from a hospital setting, should be devised to suit the needs of the person with mental illness. Care should be taken to present it as an attractive option for the person who is ill rather than as a punishment or as a relief for the family. The only respite care available in the ACT insists that the clients provide food and prepare their own meals. There is no support worker present outside of business hours. This would not be suitable for members of my family even when they are comparatively well. Support is needed with supervision medication, nutritious diet, regular meals, housework etc.

Unfortunately **early intervention and prevention** were not available for my son, even though he should have been recognised as "at risk" because of family history.
I know that big improvements have been made in this regard, but I doubt if they are so well coordinated as to avoid some people falling through the cracks.

The extent to which unmet need in supported accommodation, employment, family and social support services is a barrier to better mental health outcomes

My experience is mostly with schizophrenia. There seems to be no knowledge of how many people need **supported accommodation**, just a presumption that most people will eventually be able to live, with minimal support, in their own flat. This is a good ideal, but we really need research to see how and when this is possible and when it is not. Many families find that, much as a relative would like to live alone, it is just not practical.

In the ACT, there is only long term 24 hour staffed accommodation for those with extreme need. Short term 24 hour staffed accommodation seems to have pressure on its availability. It seems to be reserved for those who need transitional accommodation after leaving hospital. Other supported accommodation houses, which have are staffed in business hours or have staff who can be called as required. This allows incidents that could have been minimised by staff attendance to escalate. There are only usually no vacancies. Some places also have restrictive criteria for entry.

I do not think that anyone knows what the demand really is, how many people are homeless, how many people are living in conditions which either aggravate their mental illness or their physical illness or how many need different accommodation from that which they have.

Employment opportunities are very limited. There is a local agency that finds work for people with mental illness. The rumor is that the success rate is very small. They tend to cater for those people whose symptoms are well under control. There is an acknowledged tendency to underestimate the number of people with mental illness who can work. There is, at the same time, a tendency by some interested parties to overestimate the extent to which some people can work. Research and pilot programs are needed to determine accurately what can and should be done. There is some evidence that the requirements of some government funding actually works against appropriate help being given to people with mental illness to find work.

Comorbid Conditions Studies in the UK and WA have identified high rates of co-morbidity and high mortality rates among people with schizophrenia. Causes of premature death include cardiovascular disease, complications from diabetes and cancer, as well as suicide. Speculations about the reasons for this include increased levels of predispositions to the various conditions, side effects of medication or lifestyle resulting from social exclusion, stigma or the symptoms of the illness.

Until recently, very little has been done to improve the general health of people with schizophrenia or to minimise the effects of co-morbidity. A pilot program exists in the ACT and some work is being done in Melbourne and presumably in WA, but many people live without care for their general health. The demise of bulk-billing in some areas aggravates this. Is research being done to determine why such comorbidity and low life-expectancy exist? Figures for life-expectancy from overseas studies suggest a rate approximately 20 % below the rest of the population, that is similar to life-expectancy for indigenous Australians.

Training of and Support for Family Members.
Training needs to be specific to the set of symptoms involved and to be family based. It needs to inform and empower family members, building positive, but realistic attitudes and developing interpersonal and problem-solving skills. In the past there has been too much emphasis on the “plight” of carers, their “self-sacrifice”, their “heroism”, etc. This has been unhelpful, counterproductive and isolating from the mainstream community. Training also needs to engender respect for the person who is ill, It needs to include strategies for lifting his/her self-esteem and strategies for attaining as much independence as possible for the person who is ill as well as aiming at including him/her in mainstream community life.

Too much emphasis has been placed on the needs of the carer rather than on balancing the needs of both parties.The actual use of the word ”carer” does not show respect for the people who are ill. It takes from their self-esteem, independence and their vision of themselves as belonging in the mainstream community.

I could make further comments, but I suspect that, in doing so, I would be mostly reiterating points that the committee will hear many times over.

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