

16th April, 2005

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The Select Committee on Mental Health
Australian Senate
Parliament House
CANBERRA ACT 2600



To whom it may concern

Response to Inquiry by the Senate Committee on Mental Health

I am writing to you in response to the above enquiry as a community member but more importantly as a carer of a parent with a mental illness. My parent became unwell when I was 6 years of age (therefore I was a **Young Carer**); I am now 45 (an **Adult Carer**). I come from a **non-English** speaking background where our first language is Italian; I have worked in the **Indigenous** Sector and am aware of Mental Health needs in this arena. With all of this behind me, I feel that my views are of importance. Apart from all of this I am Co-convenor of a small NGO, Children of Mentally Ill Consumers (COMIC), I have enclosed a flyer for your referral and a Supporting Our Family Kit, which we developed in 2001.

Having read the initial letter received from Ian Holland, on 22nd March 2005 I wish to respond to the particular references.

a. I feel that the National Mental Health Strategy and resources have been excellent but **not taken overtly seriously**, my explanation of this is that when the following reports on state achievements was put together (Out of Hospital, Out of Mind) it is obvious that **various States have not achieved a great deal**, in particular SA (where I am from), therefore indicating strongly that there has **not been appropriate uptake of recommendations**. It is common knowledge within the Consumer and Carer networks in SA that we are at least 10 years (if not more) behind States such as Victoria, NSW. With respect to **funding** between all levels of government, once again this **seems disproportionate** considering there are floundering States at different levels, i.e. if one state is so far behind, why is it so? and therefore what funding/support is necessary to bring it up to the highest level? There seems to be **no mechanism working effectively for accountability** or Federal acknowledgement that **some states are not achieving outcomes** therefore requiring a boost along (with either funding or appropriate leadership)

b. My response to this is, that with increase in early identification nowadays we as a country, community, support structure etc. have **not invested enough money or time, it has not been invested in the past, and it is not now.** With statistics such as 1 in 5 people developing a mental illness within their lifetime being a starting point, it is obvious that **we are/have not been prepared adequately. I do not believe** for one minute that when initial costing for de-institutionalisation began there was **adequate forethought of ongoing needs of the acute or chronic mentally ill.** I also strongly believe that with the practice of in and out of hospital as quickly as possible, this does not allow enough time for certain individuals to adjust to medication and I know for a fact that the **carer often has no idea** what they may be in for on **release of the cared for person.** I know that there is **inadequate community care,** this is evident with the increase of identified need i.e. the increasing public awareness about mental illnesses and also carer needs, young carers, the homeless, crime, unemployment, education etc. With regard to **crisis care** I am always hearing of **the lack of availability, transport issues** (such as the police are brought in). **Respite demand is high and will continue** to be.

c. At this stage I feel that there is a **lack of coordination and delivery of funding,** I substantiate this fact because I see so many services that have not received increased funding and yet the demand for their service has increased and others that are more bureaucratic receiving funding when all they produce is more paper work. I see Services/NGO's having to compete (at times negatively) to achieve funding. All of this is time consuming and taking away from what is needed, service provision at ground level to the consumer/carer. There is also a **lack of uniformity,** from a consumer/carer perspective this involves having to do a great deal of leg work at a time when it is inappropriate, when one is unwell, trying to recover or caring.

d. I see each role being **independent** but it would be beneficial that they communicate / share information with each other.

e. Unmet need in supported accommodation, employment, family and social support services has enough evidence supporting the barrier to better mental health outcomes. Where I see pitfalls is still the **lack of supported accommodation, lack of employment and the lack of social support services.** With de-institutionalisation I do not see the equivalent supported accommodation being made available in the community, what I have seen unfortunately is the very poor state of hostels where the mentally ill have lived without appropriate support/care or that the onus is on family/carer? I acknowledge though that in some instances there has been **very slow improvement.**

Employment opportunities have improved slightly with the community's understanding of mental illness but it still has a long way to go with respect to **Centrelink's policies** engaging consumer/carer needs. (I do not believe the assessment of carers of the mentally ill is addressed appropriately).

There is still a **huge lack of support services** available to the mentally ill in particular the **lack of activity based programs** at a local level – unfortunately not all people with mental illness are comfortable, engaging with mainstream community based programs. From a carers perspective it is very difficult to observe the person you care for not having anything to do or anywhere to go – there are not many services available that may pick up the consumer for an activity etc. unless the carer takes them. The burden on the carer is added upon by having to entertain, engage the unwell person for long periods of time and at times taking them away from employment because of the fear/concern they have of the neglected, isolated one they care for. This is not conducive to good mental health when it is ongoing.

f. This arena of **special needs groups** has only been **touched slightly** and requires **much more input financially**. Please refer to our work at COMIC to support this (education, support and respite). The needs of **aged care** has begun to be addressed far better than it ever has been but once again, there needs to be an **increase** in supported accommodation, support services etc. With regard to our **Indigenous Australians**, there needs to be a **great deal more work undertaken** i.e. how they perceive mental illness / mental health and the incorporation of services? Geographically Australia has many **isolated populations** and issues that **still need to be addressed**. **Co-morbidity has only begun** to be acknowledged and there is still a lack of inter-agency acceptance and understanding occurring. **Drug and alcohol** issues are becoming more prevalent but once again, there **needs be improved** inter-agency communication and supports made available.

g. Once again this area is gaining momentum but still **extremely inadequate**. The mechanisms in place at the moment are **not at all effective**. There is a great deal of information (reading literature) available but there is no structure in place to follow through the acceptance/understanding of the Carer because there is a **lack of resources** at ground level (assessment of carer understanding, needs such as respite and self care, most importantly how much caring is undertaken). What I identify as being a problem is that **if a Carer is identified** in this arena they are usually **palmed off** into a network of varied information that may not be of any relevance to them, therefore they are having to unravel all of this data until they find what may be relevant to them. This additional challenge apart from their Carer responsibilities adds to their stress and frustrations – this is not good mental health practice.

h. The role of primary health care in promotion, prevention and early detection is of the utmost importance and is and has contributed to where we are now as a society. It is very important to **continue maintenance and support** this arena. Where it comes to **chronic care management**, this is an arena, which **requires far better supports and follows through** than what is occurring at the moment. An example is my mother who has a mental illness and is now ageing – the mental health sector would like to see her removed from this arena and placed into the ageing sector that does not have adequate mental illness support mechanisms.

i. It is **very important** to have **consumer/carers involvement** at all levels and facilitating peer support and education of the mental health workforce.

We are the consumers of the services and have insight that the mental health workforce do not necessarily have. There is **expertise on both sides** and working together equates to better outcomes (recovery is one of them). Apart from this, it is set within the National Mental Health Strategy and if adhered to has proven itself to be effective. The only barrier I see occurring here is that there is not the best mechanisms in place to support consumers/carers to succeed, what I mean here is that there is an expectation from services (be it government / non-government) that we (consumer/carer) have skills to participate, have the freedom (other obligations to be met and in the instance of a carer, carer responsibilities such as taking the consumer to medical appointments, making sure they have enough food, support them in activities or taking them to these etc.), are able to / confident to use a computer, have support or someone to advocate for us when needed. All of these are necessary processes to be taken into consideration when asking for participation otherwise it will lead to failure/relapse.

j. I believe that this speaks for itself. The environment and practices purely as it stands is conducive to poor mental health. **There needs to be more health professionals available within the system,** and their needs to be the **identification and acknowledgement of the mentally ill within the system.** They require the appropriate support (treatment/medication, supervision, support, protection and care). I don't have a great deal of knowledge in this area but I believe that society also requires protection from individuals who commit a crime whether they are well or unwell but I would like to believe that if a crime is committed by an individual whilst they are unwell, if it can be proven that they are capable of living safely within the community under supervision, and are prepared to undertake the interventions necessary to allow them to be well enough, they should be given a chance to do so.

k. Unfortunately I have been exposed to this arena when my mother initially became unwell (and episodically after). It is difficult to manage someone when they are in a psychotic/paranoid state but on the other hand some of these practices contribute to escalating apprehension. There needs to be clear assessment and incorporation of other parties (carer other family members, friends) in which technique would be most appropriate if possible but if it is clear beyond any doubt that the person is a danger unto themselves/others unfortunately, there is a need for detention.

l. Over the last 5 years there **has been an increase in education** de-stigmatising mental illness and disorders thankfully to Rotary, Beyond Blue, Mind Matters, Suicide Prevention, COPMI (Children of Parents with a Mental Illness Project) Promotion, Prevention, Early Intervention strategies, movies etc. This **needs to be ongoing.** With this information being provided to people affected by mental illness and their families and carers it does and can only contribute to them not feeling isolated on the matter, in other words it helps them/us feel we are a part of society.

m. There is **no proficiency and accountability** of agencies such as housing etc. Even though we have Equal Opportunity, Discrimination Acts etc I do not believe that mental illness sits well within these Acts. I am unaware of any policies/practices that these agencies may have in place dealing with mental health even though mentally ill is supposedly under the umbrella of disability?

This I believe allows individuals, services and communities to **continue to behave inappropriately** when dealing with a person/sector that involves mental illness /their carer.

An example of this is Centrelink's assessment of a Carer applying for a Carer's pension. A carer of someone that requires physical feeding, washing etc is considered the norm but the carer of a mentally ill person who doesn't want to get out of bed to wash, doesn't care what they eat etc is not even acknowledged. It can be equally draining and stressful with similar outcomes but one carer is allowed the benefit and the other not.

n. Mental Health Research is not adequately funded at all – I understand that it is an absolutely huge area but unlike the Cancer Foundation, Diabetes Foundation and the many others, it does not have a high profile and it does not advertise. Best Practice dissemination on Mental Health seems to be coming from Beyond Blue, COPMI Project, Suicide Prevention and Auseinet – on Promotion, Prevention and Early Intervention. Mental Health has not been incorporated well into Physical Fitness, Dietary Requirements, Community participation etc. The other concern, especially from the consumer networks is the sponsorship of awards, projects etc by the pharmaceutical companies and it is often queried whether it is really a conflict of interest.

o. As an advocate, I do not believe that there has been adequate data collection and the mechanisms in the past have been very slow. To support this I highlight once again the work of COMIC, which has advocated for five years that the information required is identification of the primary carer (this may be a child/young person) identification and assessment of carer education, needs, support or respite, and also identification thereafter of the parental necessities (does this person with a mental illness require support to look after their child? etc). These questions have not been asked uniformly in all states and data has not been adequately collected and therefore there is no accurate information available. I can confirm this because I telephoned the Bureau of Statistics and asked for the number of children living in Australia that has a parent with a mental illness – the response was (and this was after a staff member spoke to a senior) “No, we don't have this, it is not an area of interest”.

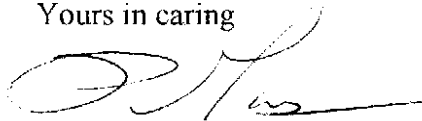
If simple information such as this has not been collected, the outcome measures, quality of control for monitoring and evaluation is questionable. Is this service working in the best interest of the consumer their carer/children and therefore if the information gathered is questionable how can there be opportunity to link funding, which is in compliance with national standards.

p. With respect to the **potential for new modes of delivery** of mental health care including e-technology, I believe a great deal is already in place it requires modification/change. The **correct questions** need to be asked initially, (this should fit within Human Rights – Safety, Food, Clothing etc) the mode should be **holistic** instead of purely focussing on an individual and the mental illness (clinical) – it should take on board the Carer whether they are partner, friend, child, service etc. I would recommend that the model of delivery be open (not open and closed) therefore being inclusive and supportive. The modes of delivery do not need to begin with admission/detention it should be **within the community i.e. GP's, school counsellors, community centres, libraries, etc.** The modes of delivery of mental health care would also benefit from **input from the clientele** with the expertise – the one's that have utilised it. It is common knowledge that a victim of crime will open to another person who has had similar experiences more so than an individual that doesn't. There is a great deal of untapped skill in mental health that could be utilised broadly and visa versa.

I wish to thank you for the opportunity to respond to the enquiry. Overall, I know that I have noted quite a great deal, but it is important that we do. My concern, as I know it is of others is that there have been many enquiries, reports, reviews etc. The Mental Health Council of Australia have produced so much and yet there is still so much that hasn't been taken on board. I understand that funding is limited but at this point in time it is important to progress, not procrastinate. It is time to modify/change practice and for the States that are floundering, they will require some leadership/directives to proceed.

Once again, thank you for this opportunity and I hereby give permission for you to publish any comments. I am available on (hm) 08 8293 1444 should you require further clarification. I look forward to the outcomes and if at all possible a copy of the final report.

Yours in caring



Paola Mason

Enc: COMIC flyer
COMIC Supporting Our Family Kit