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Dear Committee Secretary

This submission is made on behalf of the Canberra Schizophrenia Fellowship Inc (CSF) to the Senate Select Committee on Mental Health in connection with its Inquiry into "The Provision of Mental Health Services in Australia" We welcome the Inquiry and the opportunity to provide this submission.

The CSF

The CSF is a community-based volunteer non-profit organization, incorporated in March 1986. It seeks to provide effective assistance to those in Canberra and its surrounding region with a mental illness, their carers and their families. It does this by providing direct support, information and advocacy. It also contributes to assisting those with mental illness within the Australian community more generally through its cooperation with national and intra-national organizations with similar goals. Its efforts are not confined to those suffering from Schizophrenia.

The CSF has developed a number of core programs through which it provides assistance. These are (1) A Rehabilitation Program, which manages the vocational

rehabilitation arrangements under the CSF's agreement with the ACT Government. (2) A Psychiatric Services Unit Consumer Support Program, which provides support to patients at the PSU Canberra Hospital Woden in terms of securing for them personal necessities urgently required. (3) A Telephone Assistance Program, which provides a readily available facility for persons who are seeking information or advice to better enable them to deal with a pressing issue relating to mental illness (4) Programs involving a monthly newsletter, monthly meetings with guest speakers/facilitators for members and the wider public, and organising events for Schizophrenia/Mental Awareness weeks, all aimed at better informing members and the wider public on issues associated with promoting awareness, understanding, self-help, and improved management of mental illness, and (5) An Advocacy and Inter-organization Cooperation Program aimed at advancing support and improving services for those suffering from a mental illness and their primary carers.

The direct experience of CSF members and the indirect experience gained through activities of the kind referred to above provides the context in which the CSF is making this submission.

Terms of Reference (a). "The extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress.

Comment.
The CSF is mindful of, and grateful for, the efforts of governments within Australia to provide support for those with a mental illness. However, the Select Committee will have before it a great deal of documented research that demonstrates that Australia, at Commonwealth, State and Territory government levels, lags far behind New Zealand, Canada, the United Kingdom and the Scandinavian countries in terms of public funding for the mentally ill. In Australia the percentage devoted to mental "health" is less than 8% of the health budget compared with 12% plus for the countries mentioned. Why is this? Why in relative terms do those suffering from a mental illness in Australia not get the same level of recognition and support as those with similar debilitating levels of physical illness? Is it because of the ignorance and stigma that still attaches to mental illness widely throughout the community?

The result of all governments within Australia giving mental illness such a low priority within existing total and health budgets is that the support provided falls far short of the minimum needed to provide basic, humane support to one of the most debilitated and vulnerable sections of the Australian community. This is reflected across the spectrum of the interventions needed to assist the mentally ill

Unless the share of government funding provided for mental illness is substantially increased so that it at least equates with the average level provided by similar developed countries such as those mentioned above, Commonwealth, State and Territory Strategies to address mental illness will, and would, fall far short of their stated objectives. Improved efficiencies in the allocation and use of resources, while fundamentally important to pursue, would not itself achieve the level of support needed and justified. That can only be achieved by raising substantially the overall allocation of resources. This is the key point that the CSF wishes to make.

The barriers to progress are numerous because of conflicting demands on budgets and at the political level. In the CSF's view the only way to give effect to basically sound Commonwealth, State and Territory strategies on mental illness is for the Commonwealth Government to show much stronger leadership than has been the case to date. Indeed to date Commonweal leadership has been limited to Commonwealth/State Ministerial reports on strategies and standards in this area of public policy.

The CSF, therefore, recommends that Commonwealth leadership be established and involve (a) adopting a high public profile at the most senior political level to address the pervasive misunderstanding and stigma that continues to attach to mental illness throughout the Australian community. (b) providing a substantial increase in Commonwealth funding for mental illness, and (c) delivering a sufficient part of this support in a way that leverages substantial increases in State and Territory funding and improved services.

Terms of Reference (b). 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.

Comment.
The reality is that relative to need, the substantial shortage of funds devoted by governments at all levels within Australia to supporting those with a mental illness dictates that in almost all areas of care resources are stretched to the limit, inadequate or absent.

Examples of continuing difficulties include: too brief a period of acute care provided because of bed and staff shortages, inadequate post hospitalisation follow up support because of the "culture" of some private and public health professionals and/or because of the demands on those professionals, and in the ACT, no "time out" facility to assist those who need very close supervision and assistance outside of the criminal system. Below is comment on a further specific priority issue.

Continuity of Care.

Continuity of care for those hospitalised as a result of their mental illness, especially those hospitalised as a consequence of attempted suicide, or the clear intention to commit suicide, is of paramount importance. The risks of suicide are potentially very high post-release from hospital yet, within the ACT and possibly elsewhere, at best there seems to be a very patchy approach to the content and provision of patient Hospital Discharge Summaries.

The CSF, therefore, recommends that priority be given to enforcing the requirement that at the time of release from Hospital (not later) the patient is to be provided with a Discharge Summary which at the very least contains (1) details relating to the medication to be taken by the patient, (2) the time and date of the first post hospitalisation appointment with the patient's Psychiatrist and, (3) where appropriate, the time and date of the first follow-up meeting with the patient's Case Manager.

This requirement should be rigorously enforced to provide a discipline for the treating Psychiatrist, whether in private or public practice, to minimise the potential for the patient to remain unobserved by a mental health professional for some weeks with potentially fatal consequences.

Term of Reference (c). Opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care.

Comment.
The CSF is convinced that the coordination of support for those suffering from a mental illness is essential to protect their life and wellbeing. Such coordination needs to be between the full stream of health professionals and between health professionals, primary carers, their broader family group, and the wider community.

The very high potential for suicide of those suffering from a mental illness is well documented. Yet suicide prevention strategies fail to address the critical issue of patient confidentiality versus protection of the patient.

Patient Confidentiality versus Protection of the Patient.

A very difficult problem of direct relevance to suicide prevention in the context of mental illness that is left unattended because of the complexity of the ethical issues involved, yet which must be addressed in any serious attempt to minimise the potential for completed suicides, is that of "patient confidentiality".

The arguments as to why health professionals should fully protect information provided to them by, and in relation to, patients are well known and fully understood. Unfortunately this is seen as so fundamental a principle that it appears at times to take precedent over protection of the wellbeing of the patient.

For example, if a mentally ill patient is not generalising about suicide, but rather has a history of attempted suicide, reveals an intention to suicide, and is specific in detail such as method and location of a planned suicide surely this should be conveyed to the patient's primary carers and not be withheld from them. Only if patient/practitioner confidentiality is viewed as taking precedence over protection of the life and well being of the patient could a contrary view be sustained.

The CSF, therefore, recommends that the Select Committee establish a three step policy to address this critical area of protection of those suffering from mental illness viz: (1) recognising that the paramount principle to be applied is that of protecting the life and well being of the patient and not practitioner/patient confidentiality; (2) of ensuring that if a patient with a history of attempted suicide reveals to either a private or a public health professional a clear intention to suicide and details of a suicide plan, then the health professional is to alert the patients primary carer to the details of the plan unless the health professional has reason to believe that the primary carer is not sufficiently responsible; and (3) if the health professional has reason to believe that the primary carer is not sufficiently responsible to be trusted with such a confidence then that professional is to document the reason for his or her reservation(s) so that this would be available at a Coronial Inquest in the event of a subsequent completed suicide.

Terms of Reference (d). The appropriate role of the private and non-government sectors.

Comment.
Consistent with the principle that a co-ordinated and holistic approach to care for those suffering from a mental illness is essential, the CSF asserts that the private sector and non-government sector can do much more than at present to contribute to improving support to, and improving the quality of life of, those with a mental illness. The CSF recommends that the following basic "triggers" to create the circumstances under which this can be achieved be noted.

There are many examples where private sector firms have made substantial financial contributions to address physical illnesses such as heart disease, diabetes and cancer. Importantly, some leading employers have provided working conditions to assist those with a physical handicap. Yet relatively little attention has been given by the private sector to addressing mental illness, including recognition in the workplace of the particular nature of episodic mental illnesses, especially those involving psychotic episodes. The CSF is aware of the recently expressed concern of building industry unions about the workplace dangers inherent in neglecting workers with an untreated or inadequately supported mental illness. Another aspect is providing opportunities for the mentally ill to contribute and thus feel valued.

Government leadership in terms of information and education measures to improve understanding of mental illness within the broader community and within the workplace could lead the way for a much greater level of understanding and support from the private sector. This would make a major contribution to those with a mental illness by raising social connectedness, self-esteem and confidence.

In terms of non-government sectors, not for profit, voluntary organizations such as the CSF can and do play a valuable roll in assisting consumers and carers. However, because the CSF's initiatives are developed and carried out on a voluntary basis by members, many of whom are primary carers of a child or spouse with a mental illness, what can be achieved is severely limited.

Organizations such as the CSF could do much more to develop and implement programs to assist build coping skills, confidence and thus improved quality of life for those suffering from a mental illness if more grants at Commonwealth and State/Territory levels, especially multi year grants, were available for such purposes.

The grants for such purposes ought have rigorous criteria and reporting requirements to ensure that the very best of proposals in terms of objectives and proposed management, processes and reporting are successful. The payback in terms of assisting those with a mental illness would be considerable, with ongoing positive effects for consumers and the wider community.

Terms of Reference (e). The extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes.

Comment.
Those suffering from a mental illness experience deeply ingrained feelings of low self worth, low confidence and motivation and of being alone and misunderstood. This presents a major barrier to social integration and difficulties at school, in finding employment and at times in finding suitable accommodation.

For those suffering from mental illness resilience, connectedness and optimism more often than not seem to be beyond reach. Arguably, to the extent that feelings of isolation and hopelessness can be addressed, the potential for living a productive life will be increased and the potential for completed suicides will be reduced. Critical in this context is fostering opportunities for those with a mental illness to feel that they can make a contribution within the broader community and be valued.

The CSF recommends the following initiatives to achieve this (1) a change to the Social Service rules to remove the discouragement for part time employment that currently is embedded within the rules, (2) vastly enhanced vocational introduction and rehabilitation initiatives, substantially expanding the scope and nature of the modest programs currently in place, (3) broader accommodation options and (4) an increase in Case Managers to enable more assistance and support to be provided.

The CSF, therefore, recommends that government initiatives explicitly embrace a multi-dimensional approach to providing vocational introduction and rehabilitation for those persons who are disabled and who have been unable to secure gainful employment because of their mental illness.

The components of such a strategy, which in its design and implementation would necessarily have to take into account the special circumstances of those suffering from a mental illness, ought comprise: (1) To provide workplace familiarity and experience, the encouragement and identification of both private and public sector employers prepared to accept one or more people suffering from a mental illness as part time employees for a period of three months to six months; (2) To provide basic workplace skills, on the job mentoring by either a fellow employee "briefed" on the special needs of the person, or by a pool of mentors established through a Government initiative to perform this function; (3) To provide an increase in skills during the "temporary" employment period, education and training modules in a less formal and pressured environment than is the general case; and (4) An "Introduction" facility to assist those with a mental illness to identify subsequent employment opportunities.

Accommodation is also problematic. In many cases "group housing" with some shared facilities and an appropriate health professional to supervise and assist would provide a very positive environment for those with a mental illness capable of living reasonably independently with dignity, but requiring peer and lower level ongoing support. However, there are no such facilities in the ACT and there is no support at government level for such a facility. Presumably this lack of support is to a large

extent a concern that such facilities would be a step towards re-institutionalising care of those with a mental illness.

The CSF argues strongly that such a facility is fully compatible with the concept of a community-based approach to care and would provide an important option between full reliance on support and inadequate support.

Finally, to assist the process of rehabilitation and greater social integration during the rehabilitation phase, more attention is needed to recruiting and training additional Case Managers.

Terms of Reference (f). The special needs of groups such as children, adolescents, the aged, indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence.

Comment.
The "continuity of care" and "patient confidentiality versus protection of the patient" issues addressed by the CSF under Terms of Reference (b) and (c) above are highly pertinent to this term of reference.

A further major issue is that of the persistency with which mentally ill people are treated within the criminal system. High security "time out" facilities that can provide for the security of both patients and the broader community, while the primary focus is on treating the patient, is an essential and humane type of facility overlooked by the ACT Government and possibly more broadly.

The CSF recommends that the clear focus be on treating those with complex, co-morbid conditions, and drug and alcohol dependency with dignity rather than through isolation and punishment. For the mentally ill it must be recognised that during episodes of psychosis the illness is a powerful driver of behaviour, and that drug and alcohol abuse is often a form of self-medication for both psychosis and depression with long-term disastrous consequences.

Terms of Reference (g). The role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness.

Comment.
Training and support for primary carers is crucial in achieving the holistic approach essential for the effective treatment, recovery and support of those suffering from a mental illness.

The culture of primary (clinical) caring still seems to be narrowly focussed around psychiatry and nursing. It is extremely difficult for example to gain access to cost supported psychologists, the present Commonwealth Scheme for providing such access being limited and perhaps the best kept secret of the health system.

Current practice by ACT regional mental health teams is to cut off clinical support quickly, allowing very little opportunity for consultation with, and co-ordinated support from, community based services (in housing, vocational training, employment

etc.). Co-ordination of this kind is needed if a holistic approach to meeting consumer needs is to be achieved.

A holistic approach requires a more open approach too to the transfer of some consumer information to primary carers and service providers.

The CSF recommends that these issues be addressed.

Terms of Reference (h). The role of primary health care in promotion, prevention, early detection and chronic care management.

Comment.
The literature states that mental illnesses such as Bipolar Disorder and Schizoaffective Disorder often remain undiagnosed or misdiagnosed for a period of ten years or more, with the consequence that ultimately psychotic episodes are likely to be more severe and frequent. The role of General Practitioners in identifying the potential for such illnesses in patients at an early stage to facilitate early intervention cannot be overstated. To the extent feasible, governments at all levels ought encourage a strengthening of training of General Practitioners in the field of mental illness. Further, close consultation between the patients treating Psychiatrist, treating Psychologist and General Practitioner is essential given the physical and non-physical triggers that may set off a psychotic or depression episode. At a minor, but important level, the CSF can provide the Select Committee an example of an informative poster produced by MIFA which it is offering to General Practitioners for them to permanently display in Canberra Medical Centres and GP offices.

A further issue is that all too often clinical care is withdrawn too suddenly, and with an inadequate interface between health professionals and community programs that can be of assistance to those suffering from a mental illness in terms of providing peer support and building coping skills. Again, a holistic, coordinated approach to treatment and care in practice rather than just in theory is required. One stumbling block to this is that the pressure placed on individual practitioners inhibits effective communication and some systemic discipline may assist address this problem. For example, formal consultation with primary carers at the point of writing up the Hospital Discharge Summary could help ensure that support is co-ordinated and adequate.

The CSF recommends that theses issues be addressed.

Terms of Reference (i). Opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated.

Comment.
Between episodes many, if not most, people suffering from a mental illness lack confidence and have low self-esteem. During episodes their ability to function is very severely impaired. Therefore, the role that consumers can play in promoting recovery-focussed care will be limited to those who have the capacity to do so from time to time and the confidence to do so.

Having said that, only consumers can give a consumer perspective on what is and is not perceived by them to be a positive approach. However, because of the many different illnesses that make up mental illness, the vast variation in levels of severity of episodes from time to time for the individual, and the vast differences between people it has to be recognised that this is a very complex question with no straightforward answer.

There is no doubt that the side effects of treatments can be played down by treating Psychiatrists, whose main focus is on "correcting" chronic depression or psychotic episodes. However, this can be to the long-term detriment of the subject of the treatment. In such circumstances the "self-loathing" and feeling of unworthiness manifest in many suffering from mental illness can be substantially compounded. In this area consumers can play a crucial role in assisting themselves and others if given the opportunity to express their feelings to someone in authority other than the treating Psychiatrist. They are less likely to convey this to their Psychiatrist for a variety of reasons including a perception that they will be letting the Psychiatrist down.

Peer support can be very important to some who suffer from a mental illness, but not to others. In theory the provision of services for consumers by consumers is laudable. However, to what extent this is feasible given the level of debilitation suffered by many is unknown.

The importance of adequately educating the mental health workforce in both technical skills, and in having some insight to the world as seen by those suffering from the various manifestations of various mental illnesses is crucial.

The CSF recommends that these issues be addressed.

Terms of Reference (j). The overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people.

Comment.
The overrepresentation of people with a mental illness in the criminal justice system and in custody can be attributed to a number of inter-related factors. These are: (1) Deficiencies within the mental health system. (2) Insufficient use of psychologists (cognitive for improving understanding of the problem and self and coping skills), and (3) Ignorance of mental illness within the Australian community, including various arms of governments and the media, and the stigma that attaches to mental illness.

The first point to make is that with mental illnesses such as Schizophrenia, Schizoaffective Disorder and Bipolar Disorder, psychotic episodes can trigger actions that are violent and/or criminal. The CSF does not argue that having a mental illness "excuses" such actions, or that such actions go unattended. However, we do argue that the cause of such actions, namely the mental illness and associated social factors, ought be the focus of attention rather than the current focus of punishment for the crime in a criminal institution. Incarceration in a penal institution can only add to the

burden of worthlessness and shame that those with a mental illness already experience.

There is a pressing need for high security institutions outside of the penal system where offenders with a demonstrated mental illness involving psychotic episodes can be treated in a coordinated fashion and with dignity. This needs to be accompanied by "step down" facilities where treatment on an ongoing basis can be managed under full time supervision. The ACT has no such facilities, nor apparently any intention to establish such facilities. The CSF recommends that this matter be addressed without delay.

The second point is that the inadequacies in early diagnosis and intervention, inadequacies in the period of acute care hospitalisation, inadequate post hospitalisation continuity of care, and limited co-ordinated ongoing support including in respect of the involvement of cognitive psychologists all contribute to the overrepresentation of people with a mental illness in the criminal justice system.

Finally, ill informed members of the public, fuelled by the tendency of some media to focus on the violence and criminality of the mentally ill without balancing this with facts about the majority who are not violent or criminal, together with inadequately trained officials called to a "situation" can inadvertently compound the behaviour of a mentally ill person and thus the offence. Further improvement in the training of officials, more balanced and less sensational media coverage in respect of mental illness, and government leadership to address the stigma that attaches to mental illness will all assist.

Terms of Reference (k). The practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimising treatment refusal and coercion.

Comment.
At face value the detention and seclusion of a person suffering from a mental illness is inhumane. However, there are circumstances where detention and seclusion may be essential for the wellbeing of the patient as well as for the protection of the wider community. However, it is essential that in such circumstances the period of detention and isolation be kept to a minimum consistent with the effective treatment of the patient, and that the treatment of the patients illness is the overwhelmingly primary concern. Under no circumstances could any caring society condone the detention and seclusion for the simple purpose of "removing" a perceived threat.

Terms of Reference (l). The adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers.

Comment.
Education is essential in the quest to de-stigmatise mental illness. Until mental illness is de-stigmatised those who suffer from this illness will continue to feel even more isolated and unworthy than need be the case.

Much has been done to inform consumers and carers and an excellent campaign has been conducted within schools in the ACT over recent years so that many more young people who are, or may in future be, directly or indirectly involved are better informed and less likely to adopt a stigmatising attitude. However, little change is evident in general community attitudes, especially in the workplace. The CSF recommends the adoption of a much broader campaign at political level along the lines of the campaigns for anti-discrimination and in respect of drugs aimed both at the community in general and at the workplaces.

Terms of Reference (m). The proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness.

Comment.
The de-institutionalisation of mental health care has put a great many agencies on the front line of having to "do business" with people who suffer varying levels of disability from their mental illnesses. These agencies were not systematically prepared to be able to conduct this "business" in an understanding way. The result has been a significant spread of low-level stigma by the staff of these agencies who tend to blame the "victim" rather than the system. This is the cause of a great deal of unnecessary stress for sufferers of mental illness. The CSF recommends that all staff in such agencies be trained to deal in an understanding way with clients suffering from a mental illness.

Terms of Reference (n). The current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

Comment.
Australia conducts some of the worlds leading research into mental illness, for example, at the University of New South Wales St. Vincents Hospital. However, clearly to the extent that the level of research can be increased the potential for improved diagnosis, treatment and care will increase.

The CSF does not have the data to enable us to compare research support for mental illness with other illnesses in terms of their impact on the Australian society or long-term net costs to budgets. Nor can we compare Australia with other like countries. However, given the level of disability of some mental illnesses compared with even the most severe of physical illnesses, together with the level of incidence of mental illness within the Australian community the CSF would implore the Select Committee to commission such a comparison and address any shortfall that becomes evident.

The CSF is unable to give an informed comment as to the extent that best practice is disseminated, but clearly best practice is not universally applied in the ACT, hence our earlier comments in relation to improvements in terms of continuity of care and in regard to increased use of cognitive therapy.

Terms of Reference (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.

Comment.
Data collection and recording in the field of mental health is very poor, leaving scope for a great deal of improvement. The CSF recommends that this be addressed as a priority. If policy outcomes and key elements of community need cannot be measured, then policy cannot be well informed with the likelihood of wastage or inefficient use of tax-payers' funds.

The CSF advocates the establishment of a nationally consistent data system involving standardised approaches to the collection, reporting and recording of data. The data set ought allow for the measurement of the key strategic outcomes sought by governments in their strategic plans to determine if the policy outcomes sought are being achieved, expenditure on "mental health" in aggregate and by major activity (research, hospitalisation, community contributions etc). This of course would dictate the need for compatible systems within and between community agencies.

Terms of Reference (p). The potential for new modes of delivery of mental health care, including technology.

Comment.
The CSF has no specific comment to make in respect of this Term of Reference.

Case Study.

(Text to be provided.)

Summary Comment.
The issues raised and suggestions made in this submission are not academic and do not represent some utopian wish list. They are based on the hard experiences of people who live with mental illness and the anguish that accompanies mental illness day in and day out, either as consumers or primary carers of a loved one. Many have experienced the devastation of a child or partner with mental illness committing suicide because for them the pain was too hard to bear.

The CSF would be pleased to provide further detail on any matter raised in this submission should the Select Committee so wish. Our deepest hope is that this Inquiry will result in a much better understanding of mental illness within the Australian community, substantial increases in funding and improved services for the mentally ill.

Yours sincerely

Ian Morison
President