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

SUBMISSION TO SELECT COMMITTEE ON MENTAL HEALTH

Dear madam/sir

I am making this submission in three capacities:

- as a person who has had clinical depression for approximately eight years,
- as the mother of two sons with serious mental illnesses and primary carer of one of them, and
- on behalf of my sons in relation to the care they receive.

My sons and I live in the ACT.

Generally I consider that mental health services are inadequately resourced. Facilities, services and stafifing are not adequate to meet the needs of either the people with a mental illness or their primary carers.

Recommendations made throughout this submission are collated at the end with a brief indication of the terms of reference relevant to each.

Issues surrounding my clinical depression and care

In relation to my own mental illness, I attend the Depression Support Group run by the ACT Mental Health Foundation (MHF) which is funded by the ACT Government. Otherwise I arrange and pay for my own treatment and care. My main concerns about mental health services are:

- the high cost of psychological counselling. My anti-depressant medication causes significant impairment of my memory and organisational skills. With regular counselling I might be able to reduce or cease taking anti-depressants but I can't afford psychological counselling even with the $50 refund provided by my private health fund. My annual net medical expenses are already about $7000. Medicare Plus also provides reimbursement of $50 for up to five counselling sessions in a year but five sessions is not enough and it is still expensive. Psychological counselling is only available for a short period through ACT Mental Health Services. *I consider that psychological counselling should be covered more fully by Medicare*. R1
- the lack of care available to me when I left hospital after a suicide attempt in 1997. I was seen briefly by a social worker before discharge and I told her that I would be seeing a private psychiatrist. I live alone, had no support at home and could not get an appointment with a psychiatrist for four months. I received no post-discharge follow-up. *I consider that post-discharge care should be available to all people at risk of suicide*. It seems that more educated or more articulate people are being discriminated against because we may appear to be capable of looking after

> themselves – and that is indeed the impression we give – but in fact we still need help and support. Recently a friend of mine had a similar experience: he received no post-discharge support in spite of his long history of suicide attempts, and he was refused the services of a Mental Health Clinical Manager. R2

I also have significant concerns about the way employers treat employees who suffer an injury at work. Invisible injuries such as overuse injuries, back injuries, chronic fatigue and fibromyalgia are all likely to be followed by severe depression because of the physical pain and significant losses associated with these illnesses from the outset, for example loss of capacity to do things both at home and at work, loss of career, loss of social contacts. I suffered an overuse injury in 1996 and I was later diagnosed with major depression and anxiety. Previously, I had been a high-functioning member of the community with not the slightest suggestion of depression or anxiety.

My physical condition was made worse because my employer would not support my claim for workers' compensation and this meant I received little treatment in the early stages. My condition rapidly deteriorated into a chronic pain syndrome and therefore my depression also deepened and has become chronic. The adversary nature of the workers' compensation system also added to my depression.

My experience is typical of that of many of my friends and acquaintances, whose employers also essentially dismissed them as malingerers. In the end, my compensation claim was accepted. I received a small payout of my entitlements and members of the legal profession were the major beneficiaries.

If employers and their insurers treated all workplace injuries seriously and enabled their employees to receive treatment in the critical early stage, most employees would be able to get back to work sooner and their injuries would not be aggravated. Above all, if injured employees were treated with respect, they would be unlikely to develop depression and be off work for long periods. This approach would reduce the cost of compensation cases, especially the cost of legal representation and advice. It would also reduce the cost to the community of people unable to work because of chronic physical conditions and associated mental illness. R3, R4

Supervisory staff, managers and employees in all workplaces, including insurers, need more education and training about mental illness. This might decrease workplace harassment of people with mental illness and reduce their feelings of alienation. R5

Issues relating to the mental health services available to my elder son

My elder son was diagnosed with paranoid psychosis in about 2000. He is 32 years old, lives independently and appears to be able to support himself with casual computer-related work. As soon as he was diagnosed he refused treatment by making himself uncontactable. He also cut himself off from all family members and from friends. He makes occasional contact with his father in another capital city. I haven't seen him since then except for a few sightings from a distance. His paranoid delusions are associated with certain socially unacceptable behaviour which brought him to the attention of ACT Police and ACT Mental Health some years ago. Since then he appears to have learned to avoid drawing attention to himself. He has an extremely high level of intelligence but has probably suffered from Asperger's Syndrome, a form of high-performing autism, since childhood. He receives no support or treatment.

When my son was born little was known about Asperger's Syndrome because it only started to be recognised in 1981 (Attwood, 1998). Nevertheless it is disappointing that the counsellors employed by my son's primary school, high school and secondary college were unable to recognise anything more than social immaturity and they took no action to address even that. Asperger's Syndrome is not a mental illness but when it is first diagnosed in adults the person has often been misdiagnosed with schizophrenia or paranoia (*op.cit*, pp.148-149).

The loss of my intellectually brilliant son to this incapacitating syndrome and possibly also to mental illness is an immeasurable loss to society. To avoid such losses in future, not only to Asperger's Syndrome but to other as yet unrecognised developmental disorders, *it is essential for all primary schools, high schools and secondary colleges to employ full-time psychological counsellors with sufficient funding to enable them to keep absolutely up-to-date with new developments in their field including rare new conditions in child and developmental psychology*. *Pre-school teachers should also receive regular in-service training to enable them to recognise developmental disorders including rare new conditions in child and developmental psychology. Sufficient funding should be available to public community health services to provide the most up-to-date therapy for children and youth diagnosed with rare developmental disorders such as Asperger's Syndrome*.
R6, R7, R8
Furthermore, counsellors in primary and secondary educational institutions should see their role as working in partnership with parents. Parents know their children better than any teacher or counsellor can, and would generally be able to provide much additional information to help in diagnosing any disorder in their children. Fortunately the 'blame' model popular from the 1960s to the 1980s has now gone out of fashion: it inhibited a great deal of potentially useful cooperation between parents and school counsellors. R9

At university my son received some counselling which ultimately led to his diagnosis. However the counselling evidently did not prepare him at all to accept that treatment was in his interest, and in that respect his counselling was a failure. My son also had contact with the person in his university residence charged with pastoral care of students, and although this person was understanding and sympathetic, he was not sufficiently well-informed about what actions he might suggest to my son. I therefore consider that *psychological counselllors in tertiary educational institutions should be funded adequately to ensure they can keep up-to-date with new developments in their field including rare new conditions, with recognising early warning signs of serious mental illness and with encouraging articulate patients to accept their condition and the treatments likely to be recommended*. *Academics, teachers and people in university residences charged with pastoral care of students should also be funded adequately for in-service training to enable them to recognise early warning signs of mental illness or other rare conditions.*
R10, R11

Provision of adequate funding for in-service training of psychological counsellors and other staff in educational institutions would indicate to the community that governments are serious about mental health in our society and would help alleviate the stigma associated with mental illness.

At the present time I don't know if my elder son recognises that he might benefit from psychological counselling. If he does, I understand that he would be unable to afford it.
R1

I can think of only two other routes through which my elder son gain might gain access to appropriate treatment. The first would be by again coming to the attention of ACT Mental Health through the police and becoming subject to an emergency treatment order – a frightening, disempowering and undesirable process. The second would be by learning about specific mental illnesses and their treatment through a *general public education campaign aimed at raising the community's understanding of mental illnesses and reducing the stigma attached to mental illness*. *A separate public education campaign* *should also be targeted at young adults who already have symptoms of a mental illness but who do not want to accept that they need help – a very common occurrence. This campaign would, inter alia, explain the treatments available, their benefits and side-effects, and services available to help people to gain and retain employment*. R12, R13

Issues relating to the mental health services available to my younger son

My younger son, aged 30 years, has severe chronic schizophrenia. He has a Clinical Manager and psychiatrist provided by ACT Mental Health Services. He is on a long-term treatment order of the ACT Mental Health Tribunal and his finances are managed by the ACT Public Trustee. He has been hospitalised from time to time in both the secure and open areas of the Psychiatric Unit of The Canberra Hospital. In 2003 he spend nine months in the secure section of Hennessy House in an unsuccessful effort to help him overcome his dependence on cannabis and to improve his independent living skills. He is a highly intelligent person who unfortunately rejects most interventions. With his current level of support he is unlikely to work again. He receives a Disability Support Pension.

He has been accepted into a Pilot Program to improve the general health of people with a mental illness by providing him with regular access to a General Practitioner for 12 months. He is overweight, smokes heavily, has heartburn and reflux, has poor dental health, needs spectacles but regularly loses them, and gets bronchitis regularly. He is likely to have high cholesterol levels. He does not appear to have benefited from seeing the GP yet. *If the pilot program is not continued I would be concerned to see him lose chronic care management*.

R14

He is unable to live independently in a satisfactory way. He lives in abject poverty because of his addiction to smoking, his occasional use of cannabis, and the debts he continues to incur because he doesn't accept the reality of his condition (e.g. phone bills, parking fines). Debts which come to the attention of the ACT Public Trustee are repaid in tiny instalments out of his Disability Support Pension leaving him with $80 a week for cigarettes, food and other living expenses. I acknowledge that it is important for people to bear the consequences of their actions such as incurring parking fines. However when those actions are caused predominantly by the person's illness, any associated costs should be seen as part of the cost of having that illness. No person should be sentenced to live in poverty because of their illness. I consider that *Public Trustee administration of a person's income should not be allowed to reduce that income to below subsistence level*. In those circumstances, the Public Trustee should be required to report the deficiency in income to Centrelink, which would then take responsibility for costs associated with the poor functioning in society of people with mental illness. *Centrelink should be made aware of how much "take-home pay" the Disability Support Pension provides for people with a mental illness, and the pension should be topped up to ensure that people with a mental illness are not living in total poverty*. R15, R16

Research has shown that smoking in moderation has some benefits to people with schizophrenia. Further research is investigating which component of cigarettes has this beneficial effect and, hopefully, this might result in improvements to medication for people with schizophrenia. In the interim, the cost of cigarettes is a major contributor to my son's poor nutrition. I consider that the *Disability Support Pension should incorporate a small supplement to partly cover the cost of cigarettes for people with schizophrenia, if their psychiatrist recommends it*. I am fully aware that this recommendation runs directly counter to health warnings about smoking. However I consider that the special circumstances of people like my son justify this extraordinary measure. R17

My son rents in the private market. When he returned to Canberra after living for about 18 months in another capital city, he was not eligible for a government flat. He is on the waiting list for public housing. He has caused substantial damage to his flat and it is usually in a disgusting condition. He tries from time to time to keep it clean but is not able to sustain the motivation. He rejects all kinds of support including the idea of supported accommodation because he sees it as intrusive and insulting to his self-respect. *A much wider range of supported accommodation should be made available, particularly accommodation providing minimally intrusive support to respect those who desire a greater degree of independence*. R18

He also rejects specialised employment services aimed at helping people with a mental illness find and retain employment. In about 1999 he found himself technical employment with a local internet service provider but because he stopped taking his medication and ceased contact with his Case Worker, he only kept the job for 3-4 months. There are several good reasons why he rejects employment assistance: he is reluctant to let a potential employer know about his illness, the staff of employment agencies are less intelligent than he is, and the kinds of employment offered are menial and routine. *All of these issues should be addressed by specialised employment services for people with a mental illness*. R19

My son also rejects social support services such as self-help groups, social groups for people with mental illnesses generally or schizophrenia in particular, and services provided by community centres, whether for the general populace or targeted at people with a mental illness. Public education about mental illness might eventually help my son feel less aware of the stigma attached to mental illness and therefore less depressed about his condition and his life. *Meanwhile more action should be taken by providers of these services to reach people who could benefit from their services but who are reluctant to engage. For example, with adequate funding, service providers could employ more people to take on a one-on-one outreach role, visiting consumers in their own homes and taking them to activities*. *Mental Health Clinical Managers could be more proactive in encouraging consumers to use such services*. In the ACT, Clinical Managers (previously called Case Managers) used to provide these services to small degree. Now, with volunteers providing such services, demand far outstrips the supply of volunteers. Because voluntarism is declining as the Australian population ages, *governments need to act now and provide adequate resources to existing service providers to enable them employ and train paid workers*. R20, R21, R22, R23

At present my son receives no assistance to help him deal with his drug dependence apart from ineffective exhortations from his Clinical Manager to stop using cannabis. In the past, one or two members of the Crisis Assessment Team have even condoned his cannabis use – an extremely unhelpful attitude I thought, because I know how destructive cannabis is to him. Predictably he rejects support services for people with drug dependence. However*, if providers of these services had adequate funding, they could employ more people to take on an outreach role, similar to that recommended for providers of social support services.* R24

In relation to your term of reference (m), of all the people I have seen dealing with my son, the worst examples of inappropriate behaviour have come from several medical practitioners in private general practice. For example, they have been impatient, become visibly exasperated because he was unable to do simple things such as put a thermometer into his mouth and keep it there, treated him as very stupid, or treated me as very stupid. I consider that *regular in-service training should be available to all medical practitioners to ensure they are well-practised in dealing with people with a mental illness. This should also be addressed adequately in primary medical training*. R25, R26

Your term of reference (p) relates to the potential for new modes of delivery of mental health care, including e-technology. In general, I consider that mental health care using new technology, such as depressionet.com.au or moodgym.anu.edu.au, Is primarily of benefit to people on middle and upper incomes. While people on low incomes and those below the poverty line may be able to obtain some access to the internet through social and other support services, such as *The Rainbow* Club House in the ACT, this access is not regular enough to be of any real help. Although my younger son rejects almost all support services, I believe he would access mental health care over the internet if he had free access to the internet in his home. He is very computer literate, very concerned about his privacy and would like to manage his life by himself (although he is not able to do so). Accessing mental health care by himself in the privacy of his own home would suit him very well. I therefore consider that *people with a mental illness who are interested in accessing mental health care over the internet should be provided with a cheap second-hand computer and a certain amount of free internet access in their own home*. R27

Use of the term 'consumer'

I wish to lodge a strong objection to the use of the term 'consumer' in the health context generally. To consume something generally implies both a degree of choice and an element of pleasure: "I'll have some mental health care please. Oh, yes! Thank you. How lovely it is to have a mental illness!"

Nobody in the world wants to be in a position to have to consume mental health services because nobody in the world would choose to have a mental illness. And there is certainly no pleasure.

Surely there is a better word out there. Even 'client' is preferable. The word 'patient' undoubtedly went out of favour because it disempowers the individual seeking treatment and help, and it is important for people to feel they are in a partnership with their doctor and treating team. But the word 'consumer' simply gives me indigestion. R28

Issues relating to my role as primary carer

I have received adequate training for my role as carer of a person with a mental illness through the *Skills for Carers* program run by the Canberra Institute of Technology. I also regularly attend the *Serenity* group, an independent support group for families and friends of people with a mental illness which helps me to have a positive outlook on life and to enjoy my own life regardless of how well or unwell my son is.

However caring for my son is complex, psychologically demanding and financially draining. Just as a person with a physical illness needs help with physical care, a person with a mental illness needs help with psychological care. I need to encourage my son to learn how to live with his illness. I need to maintain a hopeful outlook: to hope that my son will one day be able to look after himself better, that he will learn to develop little routines for doing everyday tasks, will learn how to manage his finances better, how to make better decisions and learn from his mistakes, will perhaps even learn that his delusions are not real. Hope is essential because I expect to die first and I hope my sons will be OK after I die.

The special skills required to care for a person with a mental illness include very sensitive communication and interpersonal skills, especially listening skills; a very good understanding of the person's illness in both its generalised form and the specifics of the individual case, including understanding of the constant changes in symptoms and behaviour, and of suicide risk factors; understanding of adult learning principles; and the ability to put these into practice on an ongoing basis with a great deal of flexibility and patience.

Clearly the kind of care my son needs is very different from the physical care needed by a person with a physical illness. Unfortunately these differences are not recognised in the way eligibility criteria for Carer Allowance are structured. Twice I have given up applying for Carer Allowance even though I desperately need some financial assistance to cover the costs of caring for my son. The eligibility criteria are so heavily focussed on caring for a person with a physical illness, I just could not see how I could meet the criteria. I spoke to staff in Centrelink and also to the Carers' Association but did not get any helpful advice about how I would meet the criteria until I recently found out accidentally where the Centrelink Carers Team is located and I wrote to them directly.

Centrelink counter and telephone staff should be adequately trained to answer the full range of questions they are likely to be asked. If this is not possible, they should refer enquirers to staff with more detailed knowledge rather than giving an inadequate reply. R29

After eventually locating a person in Centrelink with a reasonable knowledge of Carers' Allowance, I now plan to apply for the allowance. However I still have a very low expectation that it will be approved because the kind of care that I give is so different from the physical care which the application form concentrates on. I therefore consider that *the eligibility criteria for Carer Allowance should be reviewed to take account of the complex kinds of psychological care needed by people with a mental illness.* R30

Mental health research

Mental health research is inadequately funded, particularly in relation to the proportion of the population who suffer from mental illness. More research should eventually reduce the enormous cost to the economy of the loss of productivity among young people diagnosed with schizophrenia and other severe psychotic illnesses at the very beginning of their adult life. For example, the link between cannabis use and development of schizophrenia and other severe mental illnesses is very evident to me and most of the relatives of people with severe mental illnesses whom I have met over the past 10 years. However, it is only in the past one or two years that a small number of research studies are beginning to be published on this issue. R31

Further, a great deal of research into mental illnesses, much of it from the USA, is disseminated in the ACT by summaries in the Canberra Schizophrenia Fellowship (CSF) Newsletter yet there is no indication that any of this research is taken seriously in Australia. Australian researchers do not appear to be attempting to replicate this research, nor is ACT Mental Health Services trying out treatments recommended in new research. While ACT Mental Health Services is fortunately quick to respond and use new medications, non-medical interventions are completely ignored. Unfortunately one of the major issues here is cost: new medications are very expensive but the cost is borne by the Commonwealth through the Pharmaceutical Benefits Scheme, whereas the cost of new treatments involving the "talking therapies" or other highly staff-intensive interventions would have to be borne by the ACT Government. However it is not reasonable to expect State or Territory governments to bear these costs because the effectiveness of the new non-medical interventions is usually not fully proven. The costs are therefore in the nature of research or clinical trials rather than treatment per se. I consider that the *Commonwealth Government should provide funding and research support for State and Territory governments to undertake and report on clinical trials of proposed new non-medical interventions for treatment of schizophrenia and other severe mental illnesses*. R32

Summary of recommendations

No.	Recommendation	Relevant terms of reference
R1	Psychological counselling should be covered more fully by Medicare.	(a), (c)
R2	Post-discharge care should be available to all people at risk of suicide.	(b), (c)
R3	Employers and their insurers should treat all workplace injuries seriously to enable their employees to receive treatment in the critical early stages.	(b), (e)
R4	Employers should treat their injured employees with respect to help prevent employees from developing depression.	(b), (e)
R5	Managers and employees at all levels and in all workplaces need more education and training about mental illness to reduce the alienation and workplace harassment of people with mental illness.	(b), (e), (l)
R6	All primary schools, high schools and secondary colleges should employ full-time psychological counsellors with sufficient funding to enable them to keep absolutely up-to-date with new developments in their field including rare new conditions in child and developmental psychology.	(a), (f), (m)
R7	Pre-school teachers should also receive regular in-service training to enable them to recognise developmental disorders including rare new conditions in child and developmental psychology.	(a), (f), (m)
R8	Sufficient funding should be available to public community health services to provide the most up-to-date therapy for children and youth diagnosed with rare developmental disorders such as Asperger's Syndrome.	(a), (b), (c), (f), (m)
R9	Counsellors in primary and secondary educational institutions should see their role as working in partnership with parents.	(e), (f)
R10	Psychological counsellors in tertiary educational institutions should receive adequate funding to ensure they can keep up-to-date with new developments in their field including rare new conditions, with recognising early warning signs of serious mental illness and with encouraging articulate patients to accept their condition and the treatments likely to be recommended.	(a), (c), (f)
R11	All staff in tertiary institutions charged with pastoral care of students should be funded adequately for in-service training to enable them to recognise early warning signs of mental illness or other rare psychological conditions.	(a), (f), (e), (f)
R12	Public education campaigns should be held regularly to raise the community's understanding of specific mental illnesses and their treatment and reduce the stigma attached to mental illness.	(a), (l)
No.	**Recommendation**	**Relevant terms of reference**
R13	Additional public education campaigns should target young adults who already have symptoms of a mental illness but who do not want to accept that they need help. These campaigns would, *inter alia*, explain the treatments available, their benefits and side-effects, and services available to help people to gain and retain employment.	(a), (f), (l)
R14	The Pilot GP Program to improve the general health of people	(a), (h)

	with a mental illness should be continued indefinitely; if the pilot program is found to be ineffective in any way it should be improved rather than discarded.	
R15	Public Trustee administration of a person’s income should not be allowed to reduce that income to below subsistence level.	(a)
R16	Centrelink should “top up” the Disability Support Pension of a person with a mental illness when their “take-home pay” falls below subsistence level, to ensure that people with a mental illness are not living in poverty.	(a)
R17	The Disability Support Pension should incorporate a small supplement to partly cover the cost of cigarettes for people with schizophrenia, if their psychiatrist recommends it.	(a)
R18	A wide range of supported accommodation options should be made available for people with a mental illness, particularly accommodation providing minimally intrusive support to respect those who desire a greater degree of independence.	(a), (c), (e)
R19	Specialised employment services for people with a mental illness should recognise that people with a mental illness have widely differing abilities and needs, and provide services accordingly. Agencies should be structured to provide support commensurate with the level of privacy the consumer wants about their condition, and the capacity of the consumer for high-level work.	(b), (c), (e), (m)
R20	More action should be taken by providers of social support services to reach people with a mental illness who could benefit from their services but who are reluctant to engage.	(a), (e)
R21	Providers of social support services should receive adequate funding to enable them to employ more people as one-on-one outreach workers. Outreach workers should have a wide variety of interests and personal attributes so that a worker can be chosen to meet the abilities and needs of the mentally ill person.	(a), (b), (c), (d), (e)
R22	Mental Health Clinical Managers should be more proactive in encouraging consumers to use such social support services.	(a), (e), (h)
R23	Governments need to act now and provide adequate resources to existing service providers to enable them employ and train paid workers instead of relying on volunteers.	(d), (e)
R24	Providers of support services for people with drug dependence should receive adequate funding to enable them to employ more people as one-on-one outreach workers.	(a), (b), (d), (e), (f)
R25	Regular in-service training should be available to all medical practitioners to ensure they are well-practised in dealing with people with a mental illness.	(a), (h), (m)
R26	Primary medical training should provide all graduating medical students with appropriate skills to deal with people with a mental illness.	(h)

No.	Recommendation	Relevant terms of reference
R27	People with a mental illness who are interested in accessing mental health care over the internet should be provided with a cheap second-hand computer and a certain amount of free internet access in their own home	(a), (p)
R28	The Committee should give some thought to finding an alternative word to ‘consumer’ to describe people with a mental illness seeking treatment and support.	(l)

R29	Centrelink counter and telephone staff should be adequately trained to answer the full range of questions they are likely to be asked. If this is not possible, they should refer enquirers to staff with more detailed knowledge rather than giving an inadequate reply.	(i), (m)
R30	Eligibility criteria for Carer Allowance should be reviewed to take account of the complex kinds of psychological care needed by people with a mental illness.	(g)
R31	The Commonwealth Government should provide more funding for primary research into mental illness commensurate with the proportion of the population who suffer from mental illness, to reduce the enormous cost to the economy of the loss of productivity among young people in particular.	(a), (n)
R32	The Commonwealth Government should provide funding and research support for State and Territory governments to undertake and report on clinical trials of proposed new non-medical interventions for treatment of schizophrenia and other severe mental illnesses.	(a), (n)

Yours sincerely

9 May 2005