Submission to
The Senate Select committee on mental health
March 2005

From: insane australia

We would like to take this opportunity to thank the Senate for assembling this committee to look at the how current mental health service system lives up to Commonwealth mental health plans, where improvements are needed, and inviting contributions from the public to inform this very important enquiry. We are an unaligned group of mental health service users

Below is an extract from our submission to the HREOC enquiry into human rights and mental health from September of last year.

In the interests of allowing the many people who were not able to attend the consultations, *Insane Australia* urges the Commissioner to recommend that the Government establish a Standing Senate Committee, Community Affairs. There needs to be a continuing mechanism for people to have the opportunity to report and have recorded their accounts of human rights abuses, whether last week or forty years ago, in relation to public and private service provision. This mechanism needs to be able to exist after parliament is dissolved, and to continue as long as it is needed.

In the interests of establishing a mechanism that will take responsibility for ensuring all Australian mental health service provision is accountable, and where breaches and human rights abuses can be properly dealt with, we urge the Commissioner to recommend a Mental Health Commission.
We are hampered by being disbelieved in the first instance. Current mechanisms do not offer sufficient redress, justice or compensation for individuals whose rights have been abused because of their contact with mental health services, or because of their inability to access services. Services must be held accountable.

In the interests of dealing with current and past human rights abuses, and provision of ongoing advocacy, *Insane Australia* urges the Commissioner to recommend that funding equivalent to that received by organisations like *Beyond Blue* be made available to consumer groups.
Consumer self advocacy groups, organisations and individuals have insufficient funding to provide the overwhelming support needs of consumers whose rights have been abused. Nor do we have funding to provide the kinds of alternative supports that we know will work for many of us. Nor do we have funding to allow us to hold forums, conferences, communicate with each other. Without funding we remain voiceless and disconnected. Without funding we cannot participate in any of the ways that our mental health policies tell us we should be participating

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1. *insane australia*

We are a community of consumers and survivors of the mental health system in Australia who seek to give voice to the consumer-survivor experience. We receive no funding and have no formal affiliations with any other organisations, though we do have close contacts and working relationships with other consumer-survivor organisations both in Australia and internationally. Our motivations for forming *insane* can be summarised under the following headings.

1.1 Mental Health Consumer-Survivor Experience as a Social Movement

There is a growing worldwide social movement of mental health consumer-survivors that sees itself in the tradition of the civil rights movements, women's liberation and feminism, Gay Pride movement, and also the physical disabilities movements that are now recognised as communities with their own cultures, needs and rights. The rights of these other movements to speak – and be heard – in their own voices, from their own direct experience, and from within their own communities and cultures, is now generally recognised, accepted and respected in Australian society. This is not yet the case for mental health consumers and survivors.

The consumer-survivor movement is as culturally diverse as any, again, with parallels to the feminist and gay movements. *insane* welcomes, endorses and encourages this diversity of voices. One of the primary aims of *insane* is to promote the awareness of Mad Culture as a community with a culture and a unique voice of its own. We seek to promote this both among consumers and survivors as well as in the general community. With this awareness, we seek to encourage consumer-survivors to speak of their experience, in their own language, with pride rather than shame and for the general community to hear our voices with open minds and open hearts rather than with fear and judgement. We believe this will promote a much healthier dialogue and understanding of the many complex issues around mental health than is currently the situation in Australia.

1.2 Human Rights and Social Justice in Mental Health

Within this broader discourse of Mad Culture, the immediate and most pressing concern of *insane* is the widespread and systemic human rights violations in mental health in Australia today. The current, limited public debate on mental health in Australia today focuses largely on the appalling lack of resources for mental health services. At *insane* we agree that mental health services are grossly neglected in this country and that many people are dying, mostly through suicide, from this neglect. This neglect needs to be seen as not just a failure to resource an essential service but as a violation of our fundamental human rights.

But we at *insane* regard this failure to resource mental health as a second-order issue. Human rights violations in mental health in Australia occur not just because of a few rotten apples in the barrel, or because of inadequate resources. Human rights violations are ***systemic and deeply embedded in how Australia responds to mental health.***

First, in the broader community, the stigma that surrounds mental health has to be seen as a deeply entrenched discrimination against madness that requires sustained, constructive measures to overcome. A clear and strong voice from consumer-survivors, in their own language, will be essential to this task.

Second, within existing mental health services, this stigma and other discriminatory prejudices and practices are intrinsic to these services and central to the systemic human rights violations. Without a major overhaul of how we approach mental health, more resources will only further entrench and possibly worsen the current human rights abuses of mental health consumer and survivors. ***Again, the voices of consumer-survivors must be heard if these systemic human rights violations are to be addressed.***

2. Summary Human Rights Violations in Mental Health in Australia

2.1 Mental health System induced Trauma and Human Rights Abuses

Denial of services

- People in desperate need are frequently being denied access to services
- This is not solely due to inadequate resources (though the failure to resource services adequately also has to be seen in human rights terms)
- Services are being denied because people are failing to meet diagnostic criteria for services, even though they might be profoundly distressed, even suicidal
- A consequence of this is that already distressed people are being traumatised when they seek help and it is being refused

Abuses encountered within services

- Many abuses, with further trauma, occur once people enter the service system
- ‘milder’ forms of abuse include the frightening and often intimidating, even hostile, environments people encounter when they enter services – for distressed people seeking help this can be disastrous
- People frequently complain that their personal feelings are completely ignored or dismissed and that they are seen not as people but only through their symptoms
- Asking questions, seeking explanations, and especially making complaints are often seen as ‘difficult behaviour’ that is often dismissed as symptomatic of our illness or, as many consumers have often heard, as ‘the illness speaking’ – this is extremely offensive and, for many, traumatising

- More extreme forms of physical abuse include being strip-searched, locked up and isolated, physically restrained by ward staff or restraining devices such as shackles
- The main form of medical abuse is forced treatment – usually potent psychotropic drugs – that is often used to control and subdue a person's behaviour, including the punitive use of these treatments, rather than for genuine medical purposes
- These abuses are more common among involuntary patients but are also frequently used against voluntary patients coercively, often with a threat of being made involuntary if they do not submit to these 'treatments'
- Outside the hospital setting, similar forced treatments and coercion are found in the widespread and growing use of Community Treatment Orders
- A related issue, and an important human rights issue, is the frequent failure to receive genuine informed consent – many consumers have stories of being deceived, bullied or tricked into taking potent psychotropic drugs that were not appropriate for them (i.e. 'off-label' prescribing), often with harmful consequences such as distressing side-effects and addiction to these drugs
- Assault and rape in acute settings

Ejection from services

- People are frequently discharged from services prematurely and/or with little or no support or follow-up
- This includes being discharged to the street – i.e. homelessness
- There is hard data that shows that the first month (or so) after discharge is a particularly high risk period for suicides
- The lack of safe, affordable housing for these people is a major contributing factor to the suicide toll – and also for ongoing distress and further trauma, specially if discharged prematurely, with an increased likelihood of the need to be readmitted
- We must include in this category those who abscond from services, many of whom abscond in order to commit suicide – no-one is asking the question "What is happening in these wards that people are absconding from care to go and kill themselves?"

To put it bluntly, distressed, traumatised people are frequently being further traumatised by the very services that they seek help from.

2.2 Medicalisation of the Human Psyche

- Mental health is becoming increasingly medicalised under a 'mental illness' model
- This pathologises psychological, emotional and spiritual distress as a biological, medical problem, even though the evidence for biological causes of this distress is, at best, weak
- This in turn locates the pathology within the individual and therefore fails to take into account the social, cultural, family and historical contexts that are invariably significant contributing factors
- The medical model – or at least the excessive emphasis on it – leads to drug treatments as the primary mode of treatment, and these medical, usually drug, therapies are the only ones that receive any significant resources and subsidies from governments
- This emphasis on the medical model is one of the most common complaints from not only consumers but also those working in psychosocial services – the medical

model sees only the symptoms of ‘illness’ and fails to see the person, especially the social person

- A very common call from consumers is for greater attention on and access to counselling services, psychotherapies, psychosocial services, peer support groups, nutritional and so called ‘alternative’ approaches such as natural therapies, yoga and meditation etc
- Resources are unavailable to these much sought after services because the vast bulk of publicly funding for mental health is consumed by services based on the medical model – hospital wards, subsidies for doctors fees and the drugs they prescribe etc.
- The medical argument against non-medical approaches – i.e. the much touted ‘evidence based practice’ – assumes a medical paradigm which is (a) not justified and (b) self-fulfilling as the medical profession refuses to research non-medical approaches to any significant extent
- The many controversies about psychiatric drug therapies – including how some of these drugs actually induce suicidality – are actively suppressed by advocates of the medical model, despite widespread community concern about these drugs
- Finally, the medical, mental illness approach lies at the core of the stigma (discrimination) against psychosocial disability with the them-and-us distinctions that are deeply embedded in psychiatric diagnostic methods – methods which are widely disputed as being more pseudo-science than science

Many consumer-survivors, and also many non-medical experts in mental health, regard the medicalisation of the human psyche as a denial and an abuse of what it is to be human.

2.3 A Two-Tier System of Mental Health

- There is a recent trend towards demarcation between ‘high prevalence’ mental illnesses, mainly depression and anxiety, and ‘low prevalence’ one – sometimes referred to as Serious Mental Illnesses (SMIs) – mainly schizophrenia and bipolar. This demarcation and the rhetoric that is used to defend it discriminates against consumer-survivors in both categories.
- In an effort to sanitise depression and anxiety as not real madness, it discriminates both against the (so-called) low-prevalence disorders - which are portrayed is the ‘really mad’ group and people with severe psychic distress who unfortunately find themselves in the group which is sold as non-serious by definition
- It discriminates against other diagnostic categories that often fall between the cracks of this two-tired system – most notably (but not only) the personality disorders, especially Borderline Personality Disorder
- Low-prevalence disorders (the really mad) are frequently subject to involuntary detention and involuntary treatment – that is, their basic human rights are much more likely to be violated
- High-prevalence disorders (sometimes referred to, offensively, as the ‘worried well’) are being promoted as the mental illnesses that ‘normal’ people frequently get, just like we might get the flu, in an effort to destigmatise them but this often has the opposite effect of further stigmatising them as the people who consume the resources which should be going to the ‘low prevalence’ disorders.

- This, also adds further to the stigma of the so-called low-prevalence disorders – i.e. again we find institutional discrimination against the mad by the medical profession
- Current campaigns on low-prevalence disorders are motivated more by economic efficiency rather than good public health policy – i.e. GPs are being promoted to diagnose and treat these disorders which, based on the medical model, invariably means drug therapies

The emerging two-tiered system of psychiatric diagnostic categories is compounding the human rights abuses inherent in a medical only approach to mental health.

2.4 Discrimination Against the Consumer-Survivor Voice

- Mention has already been made of the frequent abuse of consumer-survivors by dismissing our deepest thoughts and feelings about our psychosocial distress as ‘the illness speaking’
- There is a rhetoric of inclusion of the consumer voice in mental health debates but the consumer-survivor experience of this, virtually unanimously, is that this rhetoric is lip-service not matched by any real commitment and certainly not by any meaningful resources to promote the inclusion of the consumer perspective
- Many consumers will tell of volunteering – usually volunteering as proper remuneration is rare – to various committees and finding their contribution was not really being sought but that they were there solely so that a box could be ticked on the procedural rules of these committees
- Many of these volunteers report that their time on these bodies was, at best, a complete waste but, more often, that they felt cheated and ripped-off – their contributions were rarely heard and virtually never acted upon
- The ‘inclusion’ on committees has been distressing for some consumers who tell of not only their voices not being heard but of finding their participation being used to endorse policies that they strongly opposed to
- It is abuse to seek but ignore the consumer voice
- It is abuse to claim consumer participation as a priority (as the Victorian Mental Health Plan does) but then to (a) not engage meaningfully with consumers and (b) fail to resource consumer forums where our voices can genuinely be heard
- In this context, it is necessary to stress that individual consumers selected by organisations like the Mental Health Council of Australia (MHCA) and ‘beyondblue’ do NOT represent the consumer voice
- In Australia we do have some genuine consumer organisations that are accountable to consumer-survivors (such as the Australian Mental Health Consumers Network (AMHCN) nationally and, in Victoria, the Victorian Mental Illness Awareness Council, as well as *insane*
- These organisations must always be consulted whenever consumer participation is sought and, furthermore, their contributions appropriately remunerated
- Hand in hand with the lip-service given to consumer participation is the lack of any genuine commitment to develop forums where consumers can meet to dialogue, formulate their own policies and recommendations, develop the necessary skills to participate effectively, and to identify representatives for the various committees and other bodies that claim to seek our voice

- The failure to resource consumer organisations contradicts that claims made for inclusion of the consumer perspective

Many of the human rights abuses and violations outlined above will only ever be addressed adequately if there is greater engagement with the consumer experience which has to be a genuine commitment by all parties, truly representative of the consumer perspective and properly supported with appropriate resources

2.5 The myth of human rights abuses arising from 'medical neglect'

- The assumptions behind this argument need to be exposed or there will be a danger that many human rights abuses will not be seen while many others will be perpetuated and reinforced
- First, the phrase 'medical neglect' suggest that there may be some negligent practitioners who are failing in the delivery of mental health service – a few 'rotten apples in the barrel'
- Although there are undoubtedly some negligent practitioners, it is a red herring to blame the widespread human rights violations on just a few miscreants
- Second, this phrase might also suggest that this neglect arises due to a lack of resources – insufficient beds, overworked and/or inadequately trained staff etc.
- This also is a red herring, even though the resources issue is critical
- The 'medical neglect' argument fails to recognise – and indeed diverts attention from – the human rights abuses that are a direct consequence of the medical approach, as outlined above
- The real medical neglect is the systemic failure of the medical approach to address the full range of issues relating to mental health and, based on this narrow approach, to institutionalise abuses that are then justified by this inadequate medicine

A medical response to medical neglect will not work

3. Recommendations

The following recommendations are an initial list of actions that would go some way towards addressing the human rights violations outlined above. Only brief outlines are given as detailed specifications for concrete actions would require further discussion and planning.

3.1 Nothing About Us Without Us

- This is the motto of the Australian Mental Health Consumer Network (AMHCN) and also of the international World Network of Users and Survivors of Psychiatry (WNUSP)
- There are other organisations in Australia that are genuinely run by and for consumers, such as the Victorian Mental Illness Awareness Council (VMIAC)
- Any enquiry – or any other body that claims to seek the consumer perspective on mental health – needs to engage with **genuine** consumer organisations
- Consumer groups that are not genuinely run by and for consumers cannot and should not claim to represent the consumer perspective

- In particular, groups such as the Consumer-Carer Forum of the MHCA and the Blue Voices network of ‘beyondblue’ have no legitimacy or authority to represent the consumer perspective as they are not independent of other vested interests in mental health
- Genuine consumer organisations such as VMIAC, AMHCN and WNUSP have a vital role to play in engaging consumers in a broad and ongoing discourse on mental health
- There is a healthy diversity of views within the consumer movement on the many complex issues in mental health – as in any social movement, this diversity needs to be encouraged and developed
- This requires much greater support than is currently received by these organisations for them to hold appropriate forums – conferences, newsletters, websites etc – where the consumer voice can be heard and our discourse developed

Current funding to consumer groups hosted and controlled by groups such as MHCA and ‘beyondblue’ is a misuse of these limited funds and needs to be redirected to genuine consumer-survivor organisations

Within the healthy diversity of views among consumers, one central theme on which there is unanimous agreement is: Nothing About Us Without Us

3.2 Standing Senate Committee to enquire into Mental Health Human Rights Violations

- *insane* recommends a Senate Commission that would be able to investigate and report on mental health human rights abuses in Australia – this would be similar to the recent Senate Commission that looked into abuses against children in institutions
- Another model for this enquiry would be a ‘Truth and Reconciliation’ commission such as was conducted in South Africa after the collapse of apartheid
- The aim of such an enquiry is that moving forward on human rights in mental health first requires an acknowledgement of past abuses
- Such an enquiry will likely reveal cases where compensation and/or justice may be need to be pursued
- Most importantly, as with Aboriginal reconciliation, Australian society needs to say a collective ‘Sorry’ for the abuses of the past so that it can move forward to ensure that they do not continue
- An enquiry of this kind is currently being proposed by mental health consumers in New Zealand

3.3 A Mental Health Commission

- *insane* recommends that a permanent Mental Health Commission be established in Australia
- This has to be much more than just an ombudsman role and needs to actively promote an ongoing discourse and community education on mental health issues, as well as, amongst other things, an independent monitoring of services, including the national collection, trending and dissemination of complaints data, and with a capacity to investigate and hold services accountable to the communities they serve.

- *insane* recommends a three Commissioner model (again like New Zealand) where one of the Commissioners must be a consumer-survivor

3.4 Pro-Active Advocacy

Consumer advocacy is already a vital component of the mental health system that supports consumers in the system, particularly in regard to their rights

- Advocacy is most effective when the advocacy organisation is a genuine consumer organisation, such as the Victorian Mental Illness Awareness Council (VMIAC)
- Due to inadequate resources, most current advocacy is ‘reactive’ advocacy – that is, advocacy for consumers after problems have already arisen
- Pilot studies have shown that ‘pro-active’ advocacy can be extremely effective in not only preventing such problems arising in the first place but also in producing better long-term outcomes for consumers and, as a result, reducing demand for expensive services
- *insane* recommends that these pilot studies be urgently progressed into much larger scale projects, which must include developing and implementing the appropriate training for this form of advocacy – again, this would best be achieved through genuine consumer run organisations

3.5 Disentangle the Consumer and Carer Voices

- In Australia, consumers and carers are often bundled together in efforts to bring the experience of those directly affected by mental health issues into the discourse
- This causes many problems for consumers as the carer voice is often mistaken as the voice of consumers and/or serves to silence the genuine consumer voice
- *insane* recognises the carer voice as an important contribution to debates on mental health, but it needs to be separated and disentangled from the consumer voice
- There are often tensions, even conflicts at times, between the quite distinct and different perspectives of consumers and carers, with resentment not uncommon among consumers when carers seek to speak on our behalf

To clarify and resolve these tensions, it is essential that consumers and carers both have their own organisations and forums for their voices to be heard without confusion, competition or conflict

3.6 Resourcing

- The consumer movement in Australia needs to be adequately resourced to bring the genuine consumer voice into mental health policies in ways that are more than the current lip-service
- The Australian Mental Health Consumer Network (AMHCN) is one organisation that has a vital role to play and requires the staff and resources to hold conferences, provide training and do research

- A single national body will not be sufficient – all states need their own consumer run organisations to provide similar services (and other ones such as advocacy) to local consumer communities
- Although the VMIAC in Victoria is a model for such state-based consumer run organisation, the VMIAC itself needs considerably more resources than it currently receives in order to provide the essential services identified above
- The argument that there are insufficient public funds for the project and services identified in this submission is simply untenable
- First, the ongoing costs of not attending to the current crisis in mental health in Australia far outweigh the costs to fix the problem – first and foremost the human costs of allowing abuses to continue, but also the financial costs of ineffective but expensive services
- Second, we know that mental health is disproportionately underfunded compared with other health services, so governments need to remedy this funding gap
- And finally, we have seen federal and state governments in recent years find more than $50 million to fund 'beyondblue' and similar amounts for expensive hi-tech research projects in mental health, along with enormous subsidies to the medical profession for mental health services that are starving resources to other vital areas in mental health, such as those outlined in this submission
- *insane* strongly recommends that funding of mental health, even within existing budgets, be examined to re-prioritise funding so that services and organisations that are currently grossly neglected are allocated a greater proportion of available funds
- In particular, *insane* recommends that existing genuine mental health consumer organisations, such as AMHCN and VMIAC, be properly funded and that funds be made available to establish other, similar organisations in regions where they are needed
- *insane* notes that just the funding that 'beyondblue' has received would be sufficient to establish a strong and vibrant network of genuine consumer organisations, which are essential to overcoming the human right violations that are currently endemic in the mental health system in Australia today.

***insane* therefore calls for an immediate allocation of state and federal funds equivalent to the funding received by 'beyondblue' be made available to genuine consumer organisations in order to redress the current discrimination against mental health consumers that underpins the human rights abuses that currently plague mental health in Australia**

There is a consumer-survivor organisation in Switzerland that calls itself 'Mouvement Les Sans-Voix' – the Voiceless Movement. While we remain voiceless we can be sure that human rights violations will continue. We call upon the Human Rights and Equal Opportunity Commission to hear the cry of consumers in Australia:

Nothing About Us Without Us